



**DIRECTORY OF NATIONAL  
INFORMATION SOURCES  
ON HANDICAPPING  
CONDITIONS AND  
RELATED SERVICES**

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June 1986



## PREFACE

This is the fourth edition of what has become a standard reference work for information providers and service organizations concerned with disabled persons. Earlier editions produced by the Clearinghouse on the Handicapped, have identified and described an increasing array of organizations which provide disability-related information, occasionally, direct services, on a national basis.

This edition, prepared by Harold Russell Associates, Inc. under contract to the National Institute of Handicapped Research, offers approximately 45 "new" organizations (described in previous editions), including groups serving specific disabilities, sources of information on technology, and organizations with a focus on independent living.

The assistance of the Clearinghouse on the Handicapped and the National Rehabilitation Information Center in identifying new organizations is gratefully acknowledged. Thanks are also due to the staffs of the organizations in the Directory; many individuals took time to insure that their services were accurately described.

As always, we welcome your feedback on the content and format of the Directory.

National Institute of Handicapped Research  
Office of Special Education and Rehabilitative Services  
U.S. Department of Education



# **THE DIRECTORY: WHAT IT IS, HOW TO USE IT**

## **Purpose Of The Directory**

The Directory has been compiled as the major reference tool for information and service providers. We hope that it will also work to enhance networking, and facilitate the exchange of information. Comments on earlier editions cited the usefulness of the Directory and urged that it be kept updated. Some users have asked that regional or local organizations be included, a request we are not able to accommodate, since the Directory would then become unwieldy in size. Also, our awareness of local operations is quite fragmentary.

## **Organizations Included In The Directory**

For the Directory, NIHR has attempted to identify and collect information on national level organizations which respond to inquiries from all parts of the nation on a variety of topics.

The organizations listed in the Directory are information and direct service providers. Because our focus is on information sources, we emphasize the information components of each organization and have included material on data base vendors (commercial companies which offer information seekers access to many computerized data bases). A few organizations listed are direct service providers but operate without geographical limitation on clientele.

In many instances, national level organizations dispense information and services through state or local chapters or affiliates. We have listed only the national address after determining that an inquirer would be referred by the national office to its appropriate counterpart on the state or local level. Addresses of local chapters generally can be found in the telephone directory.

Sports and religious organizations are listed in the appendices. We have also included a listing of pertinent data bases available through organizations described in the Directory or through the commercial data base vendors.

## **How The Directory Is Organized**

To provide the user of the Directory with an understanding of the basic purpose of the organizations listed, we have grouped them in various categories. A brief description of the type of organization found in each category along with the general kinds of information or services offered accompanies each alphabetical listing, to assist you in determining which organization(s) can best provide the information you are seeking. Some organizations could fit into more than one category. For example, many voluntary health organizations are also direct service providers. Our assignment to a category tends to reflect the primary focus of the organization or the activity which has the greatest potential for providing information.

Also, we have attempted to identify the most easily accessible place for obtaining consumer information on a particular topic. The National Institutes of Health, for example, has been placed in the section on information providers, not because their basic purpose is providing information, but because they have substantial information operations which are the most direct points of access to the Institutes.

The section on internationally oriented organizations has been expanded to reflect increased interest in communication about disabilities between different countries. Organizations having international chapters but a national orientation are generally included in a different category.

The alphabetical list of organizations will help you locate the information you are seeking, irrespective of our attempt to group organizations. Federal agencies have been identified in the list by an asterisk. (Information providers funded by the Federal government but not operated on a grant or contract basis have not been identified by an asterisk.)

## **How The Data Was Gathered**

All organizations included in the 1982 edition were asked to review the description of their services and make any necessary changes. New information providers were contacted by mail and telephone for information necessary to prepare the abstract.

## **The Index**

Please take the time and effort to read the introduction to the index. It contains some important guidelines which will facilitate your use of the Directory.

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This is the alphabetical listing of all organizations and Federal agencies in the Directory. The codes show the chapter where the organization or agency appears.

A = Advocacy, Consumer, Voluntary Health  
 I = Information/Data Banks  
 G = Federal Government Other Than Information Units  
 P = Professional and Trade Organizations  
 F = Facilities, Schools, Clinics  
 S = Service Organizations  
 IN = International Organizations  
 AR = Appendix - Religious  
 AS = Appendix - Sports

All Federal agencies are marked with an asterisk for easy identification.

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 P Academy of Dentistry for the Handicapped . . . . .  
 I Accent on Information . . . . .  
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 A Adaptive Environments Center . . . . .  
 G Administration on Aging, DHHS\* . . . . .  
 G Administration on Developmental Disabilities, DHHS\* . . . . .  
 S Adventures in Movement (AIM) for the Handicapped, Inc. . . . .  
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 A Alexander Graham Bell Association for the Deaf . . . . .  
 P Alternative Living Managers Association . . . . .  
 A Alzheimer's Disease and Related Disorders Association . . . . .  
 P American Academy of Physical Medicine and Rehabilitation . . . . .  
 P American Alliance for Health, Physical Education, Recreation  
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 P American Art Therapy Association . . . . .  
 P American Association for Music Therapy . . . . .  
 P American Association for Rehabilitation Therapy, Inc. . . . .  
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## ADVOCACY, CONSUMER, VOLUNTARY HEALTH ORGANIZATIONS

These organizations generally focus on a particular disability or condition or a group of related conditions. The information and services they provide vary widely, from distribution of basic fact sheets to sponsorship of research facilities. Most of these organizations use numerous approaches to information dissemination and direct their activities toward a diverse audience. Following are examples of some activities and services provided by these groups: information clearinghouse; legislative monitoring; peer counseling; medical referrals; sponsorship of self-help groups; provision of educational materials; sponsorship of conferences, workshops and seminars; and reports on research projects.



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**Massachusetts College of Art**  
**621 Huntington Avenue**  
**Boston, MA 02115**  
**(617) 739-0088 (Voice and TTY)**

*Handicapping Conditions Served:* Physical, mental, and emotional disabilities.

*Users Served:* Disabled persons, parents, teachers, occupational therapists, caseworkers, physicians.

*The Organization:* The Adaptive Environments Center, a nonprofit organization, offers consultation, workshops, courses, conferences, and resource materials on adaptive design. The Center's library contains a comprehensive collection of materials on adaptive design. The Center is funded through public and private contracts, donations and memberships.

*Information Services:* The Center provides free information and referral service on adaptive design. The Center's publications, for which there is a charge, include Humanizing Environments, A Primer; Design Tools for Adapting Environments; and The Picture Book of Adaptive Environments. A newsletter, Accessful Reports, is published semiannually. A variety of audio-visual products may be rented or purchased. The library is open to the public. Only members can circulate library materials; others may use materials on site. Fees vary according to the type of service and type of client, except for the library and information, which are free.

**Affiliated Leadership League of and for the Blind of America (ALL)**  
**2025 I Street, NW**  
**Suite 405**  
**Washington, DC 20006**  
**(202) 775-8262**

*Handicapping Conditions Served:* Blindness and visual impairment.

*Users Served:* Disabled persons, parents, professionals.

*The Organization:* The Affiliated Leadership League of and for the Blind of America (ALL) is a coalition of over 70 national and local membership organizations which serve the blind. The primary function of the coalition is advocacy; it testifies before congressional committees and advises Federal agencies and national private organizations on the need and rights of blind persons. ALL's main concerns are human and civil rights, and the utilization of qualified blind people in management positions.

*Information Services:* ALL publishes a bimonthly newsletter which reports on pending legislation, current hearings, new publications for the blind and new technology. A national delegate assembly is held annually which contains seminars on pertinent information to the blind.

**Alexander Graham Bell Association for the Deaf**  
3417 Volta Place, NW  
Washington, DC 20007  
(202) 337-5220 (Voice/TDD)

*Handicapping Conditions Served:* Deafness and hearing impairments.

*Users Served:* Disabled persons and their families, professionals, general public.

*The Organization:* The Alexander Graham Bell Association for the Deaf, founded in 1890, is committed to the idea that hearing-impaired children should be afforded the opportunity to develop spoken communication through the effective use of amplified residual hearing and speechreading skills. The Association's Children's Rights Program advocates educational options for deaf children and provides consultant services for families pursuing their legal rights. Through this program, volunteers throughout the country serve as knowledgeable local resources for hearing-impaired children and their families. Special divisions within the Association's membership are: Oral Deaf Adults Section, International Parent's Organization, and International Organization for the Education of the Hearing Impaired.

*Information Services:* The Association publishes a journal, Volta Review, an annual monograph, and a newsletter. It also publishes a variety of books and audio-visual materials concerning the psychological, social, and educational implications of hearing loss. The Association sponsors regional conferences and a biennial convention.

The Association maintains a library of works of both historical and current importance in the field of deafness. A lending library of current materials is available to members.

The Association disseminates printed materials and answers inquiries from hearing-impaired persons, their families, professionals, and the general public.

**Alzheimer's Disease and Related Disorders  
Association, Inc. (ADRDA)**  
70 Lake Street  
Chicago, IL 60601  
(312) 853-3060  
(800) 621-0379 (Outside Illinois)  
(800) 572-6037 (In Illinois)

*Handicapping Conditions Served:* Alzheimer's disease and related disorders.

*Users Served:* Disabled persons and their families, health care professionals, general public.

*The Organization:* The Alzheimer's Disease and Related Disorders Association (ADRDA) was founded in 1980 to heighten public awareness of this degenerative brain disorder, provide support for patients and their families, and aid research efforts. Currently, the ADRDA network includes over 140 chapters and affiliates across the country, representing over 500 Family Support Groups. ADRDA's board of directors is comprised of business leaders, health professionals and family members. Additionally, ADRDA's Medical and Scientific Advisory Board consults and monitors issues related to Alzheimer's disease.

and prevention; (2) providing family support through local chapters, affiliates and family support groups; (3) stimulating education and public awareness for both professionals and the general public on Alzheimer's disease; and (4) advocating for legislation that responds to the needs of patients and family members at Federal, state and local levels. In addition to its public awareness and advocacy activities, the national office administers a research grant program to initiate new investigations into the cause(s), treatment and cure of Alzheimer's disease.

*Information Services:* ADRDA serves as a clearinghouse for information on Alzheimer's disease. The Association publishes a quarterly newsletter which covers organizational news at the national and chapter/affiliate level, research developments, medical issues, and other items of general interest. As part of its education efforts, ADRDA sponsors a month-long public awareness campaign for National Alzheimer's Disease Awareness Month each November, utilizing radio, television and print media.

The ADRDA chapters, affiliates and support groups offer the most direct link to assistance for patients and families. Support groups are moderated by health care professionals and experienced caregivers and provide a forum for sharing information, answering questions, giving recommendations for patient care options and offering a sympathetic ear to family problems. Major chapter/affiliate activities include family help programs, such as information-sharing meetings, telephone "helplines" and public awareness campaigns. Many chapters and affiliates publish literature aimed at particular caregiving issues and serve as the local resources for national ADRDA information. Some also provide speakers' bureaus.

A nationwide 24-hour hot line provides information and links families who need assistance with nearby chapters and affiliates.

**American Amputee Foundation, Inc. (AAF)**  
**Box 55218**  
**Little Rock, AR 72225**  
**(501) 666-2523**

*Handicapping Conditions Served:* Amputations.

*Users Served:* Disabled persons, parents, attorneys, physical therapists, occupational therapists, prosthetists.

*The Organization:* The American Amputee Foundation, Inc. (AAF) provides peer support to amputees and their families. Through chapters in 31 states, AAF offers counseling, information and referral, direct financial aid in the form of grants and low interest loans, rehabilitation coordination and hospital visitation. The Foundation distributes educational and self-help material to amputee consumers. AAF has developed a 3 1/2 day peer counseling training program, certified by the University of Arkansas.

*Information Services:* AAF provides a variety of publications for amputees and their families including self-help guides, a quarterly newsletter, Ability magazine, and a medical data directory on services for amputees throughout the United States. A videotape, "One Step at a Time", is also available. Referrals are made for services for amputees nationwide including recreation, rehabilitation, medical facilities and prosthetics, for which a computerized system of equipment and certified prosthetists has been developed. A

1256 Merrill Drive  
Marshallton  
West Chester, PA 19380  
(215) 692-6248

*Handicapping Conditions Served:* Osteogenesis imperfecta and osteoporosis.

*Users Served:* Disabled persons and their families, general public.

*The Organization:* The American Brittle Bone Society (ABBS) was established in 1975 to support and encourage research and education on osteogenesis imperfecta and osteoporosis.

*Information Services:* ABBS provides free information about osteogenesis imperfecta and osteoporosis. A 16 mm educational film on osteogenesis imperfecta is available to groups upon request. The organization has a 24-hour a day counseling and referral service for families and other interested persons.

**American Cancer Society (ACS)**  
90 Park Avenue  
New York, NY 10016  
(212) 599-8200

*Handicapping Conditions Served:* Cancer.

*Users Served:* Disabled persons, parents, professionals, and the general public.

*The Organization:* The American Cancer Society supports research into the causes and detection of cancer and educates primary care physicians and the public to recognize the signs of cancer. ACS offers a variety of research project grants to institutions and personnel in every aspect of cancer research. The Society's public education programs emphasize the value of periodic checkups and cancer's seven warning signals and are carried out by ACS volunteers in homes, places of employment, community meetings, and through the media. Professional education programs, offered through literature and conferences, are designed to motivate the medical and allied professions to use the latest and best possible cancer detection, diagnostic, and patient management techniques.

ACS provides direct services to the cancer patient. These services include Information and Guidance - providing referral to Society services, community resources and specific information about cancer; Home Care Items - supplying patients with a wide range of equipment, supplies and gifts to enhance their care, comfort and recreation; Transportation - assisting patients with the task of getting to and from medical and therapy appointments; Rehabilitation - assisting patients to return to their families, communities and occupations through trained visitor and group programs such as:

- ational Association of Laryngectomees, which offers speech training and support to the laryngectomy patient (see separate entry);

- o Recovery which provides support to women with breast cancer;

by other specific programs.

All rehabilitation programs are medically directed and supervised.

*Patient Education* helps patients to better understand the disease and its management through group education programs like "I Can Cope" along with pamphlets, booklets and audio-visual presentations.

*Information Services:* The ACS medical library functions as a repository and clearinghouse of information on all aspects of cancer for physicians, nurses, and researchers. Printed materials on cancer safeguards, cancer detection, smoking, statistical information, and information on unproven methods of cancer detection and treatment are available for the lay public. The Society publishes a variety of professional journals and publications. All materials are provided free of charge, and some information is available in Spanish. The ACS divisions and units provide general information services and referrals to area physicians and hospitals.

**American Cleft Palate Educational Foundation (ACPEF)**  
331 Salk Hall  
University of Pittsburgh  
Pittsburgh, PA 15261  
(412) 681-9620

*Handicapping Conditions Served:* Cleft lip and palate.

*Users Served:* Parents, health care professionals.

*The Organization:* The American Cleft Palate Educational Foundation (ACPEF) is the teaching arm of the American Cleft Palate Association (see separate entry).

*Information Services:* ACPEF makes available a series of pamphlets written especially for parents of children with cleft lip/palate. Single copies of these publications are free; there is a charge for bulk orders. A newsletter for parents, published three times a year, discusses activities of parent groups across the country, and announces items of interest such as publications and conferences. A computer-generated topical index is provided on a subscription basis to professionals.

The Foundation also refers parents to sources of services and, if possible, puts them in touch with other parents of children with clefts in their area.

**American Coalition of Citizens with Disabilities (ACCD)**  
1012 14th Street, NW  
Suite 901  
Washington, DC 20005  
(202) 628-3470 (Voice and TDD)

*Handicapping Conditions Served:* All handicaps.

as a unified voice of its member organizations to support legislation for disabled people.

*Information Services:* ACCD answers inquiries from the public about services and about the legal rights of persons with disabilities, and offers referrals to appropriate agencies. ACCD publishes a newsletter, ACCD NewsNet, and ACCD Action alerts on important issues as they arise. In addition, ACCD has a publication list of over 20 books and pamphlets concerning disability issues.

## **American Council of the Blind (ACB)**

**Suite 1100  
1010 Vermont Avenue, NW  
Washington, DC 20005  
(202) 393-3666  
(800) 424-8666**

*Handicapping Conditions Served:* Blindness, visual impairment, and deaf-blindness.

*Users Served:* Disabled persons, parents, teachers, professionals.

*The Organization:* The American Council of the Blind (ACB) advocates legislation for the blind and other handicapped persons. Priority areas of advocacy include civil rights, social security and supplemental security income, national health insurance, rehabilitation, eye research, technology and others. The Council has 17 special interest affiliates. These include the Randolph Sheppard Vendors of America, a parents' organization for visually impaired parents and parents of visually impaired children, an organization of guide dog users, and vocationally oriented organizations for professionals (e.g., blind lawyers, blind secretaries, and blind computer programmers). ACB's 52 state chapters monitor state laws affecting the blind. The national office offers free direct legal assistance to groups in discrimination and benefits cases and to individuals in precedent cases. The Council operates "The Washington Connection," a legislative hot line offering updated information toll-free at (800) 424-8666 during non-working hours. ACB also awards scholarships to blind postsecondary students.

*Information Services:* ACB holds periodic workshops for the blind on advocacy and leadership training. The organization has information about agencies and schools for the blind, scholarships, electronic aids, legislation, and legal rights. It can often give advice about specific legal problems over the phone. If ACB is unable to give legal assistance, it will provide referrals to other possible sources. The Braille Forum, a free monthly magazine updating developments in legislation, education, technology, leisure activities and employment is available in large print, braille, or cassette, and in Spanish. Affiliates and chapters also have newsletters.

**American Diabetes Association Inc. (ADA)  
National Service Center  
P.O. Box 25757  
Alexandria, VA 22313  
(800) 232-3472**

organization for professionals and lay persons, with 58 affiliates (state and large city) and 750 local chapters. The twofold mission of ADA is to promote the search for a preventive or cure for diabetes and to improve the well-being of all people with diabetes and their families. Through its extensive research program, which supplements the Established Research Investigators Program of the National Institutes of Health (NIH), ADA attracts scientists starting careers in diabetes research and provides researchers an opportunity to develop new and innovative ideas essential in procuring long-term support from NIH.

*Information:* ADA conducts professional seminars, scientific meetings and postgraduate courses for physicians and other health professionals. It publishes a monthly research journal for researchers, and a bimonthly clinical care journal and newsletter for the clinician. For persons with diabetes, it publishes a variety of pamphlets, books and cookbooks. The bimonthly magazine and quarterly newsletter include articles on recent research, nutrition information, recipes and hints for living with diabetes. Affiliates and chapters sponsor monthly educational meetings, in-hospital orientation, weekend retreats and a summer camping program for children. They also serve as a referral source to appropriate direct care agencies. ADA offers a free information package for persons with diabetes; there is a charge for periodicals.

**American Foundation for the Blind (AFB)**  
**15 West 16th Street**  
**New York, NY 10011**  
**(212) 620-2000**

*Handicapping Conditions Served:* Blindness, visual impairments, and deaf-blindness.

*Users Served:* Disabled persons and their families, professionals, local agencies and organizations, general public.

*The Organization:* The American Foundation for the Blind (AFB) was established in 1921 to help the blind and visually impaired acquire improved rehabilitation services and educational and employment opportunities, and to aid those persons in daily living activities. Through its national, regional, and legislative offices, AFB provides legislative consultation to government agencies, and advisory services to local agencies and schools involved in direct services. AFB conducts national and local surveys on psychosocial needs of the blind, and technological research leading to the design of a variety of devices which help the blind person to lead an independent life. The Foundation manufactures (or adapts) and sells more than 400 such devices, including braille watches, measuring instruments, shoelace tools, and braille games for adults and children. AFB records and manufactures about 50 talking books per year for the Library of Congress, National Library Service for the Blind and Physically Handicapped (see separate entry).

AFB's six regional offices provide a link between consumers and providers of services. They are located in Atlanta, Chicago, Dallas, New York, San Francisco and Washington, DC.

*Information Services:* AFB publishes a variety of general interest pamphlets and films about blindness, deaf-blindness, visual impairments, eye disorders, braille, assisting the blind in activities of daily living, travel, rehabilitation, education, devices, dog guides, aging



involving blindness. Existing Living Guide to Aids and Appliances for Blind and Visually Impaired Persons are also published by the Foundation. A few publications are available in Spanish; some are available in large print, braille and cassette.

The Journal of Visual Impairment and Blindness covers research and practice reports, book reviews, and legislative and organizational news, and is published in print, braille, and recorded form. Other regular publications include the Washington Report, Long Cane News, a newsletter for orientation and mobility specialists, and a quarterly newsletter.

AFB's M. C. Migel Memorial Library contains more than 37,000 books, periodicals, and other publications on blindness. Its services are available to lay and professional people, who may borrow materials in person or by mail.

Requests for information are responded to with the organization's publications or with individual letters when required. AFB makes referrals to service facilities, local agencies and other institutions, as appropriate.

**American Heart Association (AHA)**  
7320 Greenville Avenue  
Dallas, TX 75231  
(214) 750-5300

*Handicapping Conditions Served:* Cardiovascular disorders and stroke, aphasia.

*Users Served:* Persons with cardiovascular disorders, stroke patients, health care professionals.

*The Organization:* The primary concern of the American Heart Association is the reduction of premature death and disability due to cardiovascular diseases. To this end, the AHA: (1) funds research on cardiovascular function and disease and stroke; (2) gathers information on all aspects of cardiovascular disease and stroke; and (3) disseminates the information to professionals and lay persons through its publications and the media.

*Information Services:* AHA's 2000 local affiliates act as information and referral centers. Public education and community programs focus on the early recognition, diagnosis and treatment of cardiovascular diseases. Topics include risk factors, early warning signs of heart attack and stroke, control of high blood pressure, rheumatic fever prevention, and cardiac and stroke rehabilitation. Also available to lay persons are directories of cardiac rehabilitation units. Professionals can obtain printed materials on successful rehabilitation programs and facilities, exercise testing and training, and standards for testing laboratory. Journals are published for physicians and researchers, and three cardiovascular disease newsletters are printed for physicians and nurses. Publications are available from local affiliates (from the national office for foreign requestors). There is a nominal charge for materials ordered in bulk. Some information is available in Spanish. AHA holds professional continuing education seminars nationwide. Each AHA affiliate acts as a referral agency to direct services available in its locality, such as cardiac and stroke

information, contact a local AHA office.

**American Lung Association (ALA)**  
**1740 Broadway**  
**New York, NY 10019**  
**(212) 315-8700**

*Handicapping Conditions Served:* Respiratory conditions.

*Users Served:* Disabled persons, physicians, health care professionals.

*The Organization:* The American Lung Association (ALA) seeks the eradication and control of tuberculosis and chronic obstructive pulmonary diseases, including chronic bronchitis, asthma, and emphysema. It develops materials and programs of professional and public education and research in four major areas: (1) occupational health; (2) clean air conservation; (3) smoking and health; and (4) pulmonary disease. The medical arm of the ALA, the American Thoracic Association, conducts specific research and acts as a medical advisor to the ALA and its 82 affiliates and 59 constituent (state and large city) lung associations. These offer some direct services, such as smoking cessation clinics and breathing improvement classes. ALA provides seed grants to young researchers, and fellowships and grants to universities.

*Information Services:* Printed materials, films and resource materials on emphysema, chronic bronchitis, air pollution, smoking and health, tuberculosis and other lung diseases are available free to lay and medical persons. Several pamphlets are available in Spanish. The American Thoracic Society publishes a monthly professional journal and is a source of information on pulmonary rehabilitation centers, smoking cessation clinics, and Federal and national facilities and services. Local and constituent lung associations maintain local directories of facilities and direct care providers, and act as lung information and referral centers. For information, contact the ALA at the above address or a local lung association listed in the telephone book.

**The American Narcolepsy Association (ANA)**  
**Box 5846-0122**  
**Stanford, CA 94305**

*Handicapping Conditions Served:* Narcolepsy and other chronic sleep disorders.

*Users Served:* Disabled persons, health care professionals, general public.

*The Organization:* ANA was established as a non-profit organization in 1975 to help solve the many problems associated with narcolepsy and other chronic sleep disorders. Incorrect diagnosis, inappropriate and sometimes even dangerous treatment are common for this disorder. Narcolepsy exerts a crippling effect on learning, memory, attention and motivation. The cause of narcolepsy is not clearly understood; it can strike anyone at any age and is estimated to afflict more than 250,000 persons, many undiagnosed. Members of ANA form self-help groups and hold meetings for mutual support.

Guide for the Primary Care Physician whose Patient is Afflicted by Narcolepsy, and a 27-minute, 16 mm educational film about narcolepsy entitled "Keep Us Awake."

**American Parkinson Disease Association (APDA)**  
116 John Street  
New York, NY 10038  
(212) 732-9550  
(800) 223-2732 (Outside New York)

*Handicapping Conditions Served:* Parkinson's disease.

*Users Served:* Disabled persons and their families, health care professionals, researchers.

*The Organization:* The American Parkinson Disease Association (APDA) was founded for the purpose of providing information about the various services available to patients with Parkinson's disease and for making funds available for research in new drug therapies. It subsidizes Parkinson's Disease Information and Referral Centers in 30 locations throughout the United States which provide treatment and act as local referral sources. The APDA awards research grants to universities and hospitals. In addition, each year a \$50,000 Senior Research Fellowship is awarded to an outstanding medical researcher for a three year period, to aid in finding a cure for Parkinson's disease.

*Information Services:* APDA publishes four pamphlets and a twice yearly newsletter for Parkinson patients and their families. The four pamphlets are: (1) The Parkinson's Disease Handbook: A Guide for Patients and Their Families; (2) Aids, Equipment and Suggestions to Help the Patient with Parkinson's Disease in the Activities of Daily Living; (3) Speech Problems in Parkinson's Disease; and, (4) Home Exercises for Patients with Parkinson's Disease.

The newsletter provides up-to-date information about new treatments, medications, and research. The national APDA keeps updated lists of treatment centers and self-help groups across the country. For patients in the New York City area, the national APDA office can refer to local physicians, equipment sources, home health care services, and transportation services.

**American Society for Deaf Children (ASDC)**  
814 Thayer Avenue  
Silver Spring, MD 20910  
(301) 585-5400

*Handicapping Conditions Served:* Deafness, hearing impairments.

*Users Served:* Parents and professionals.

*The Organization:* The American Society for Deaf Children (ASDC) is a membership organization. It acts as a clearinghouse for the exchange of information among parents of

*Information Services:* ASDC provides general information about deafness and raising deaf children to all inquirers. It refers new inquirers to other parents of deaf children in their own geographical areas, so that they can share their concerns and experiences. ASDC provides speakers to its affiliated groups for workshops and seminars. The organization also publishes a bimonthly newsletter, available to members, which includes information about developments in education, legislation, and aids for deaf children.

**American Tinnitus Association (ATA)**  
P.O. Box 5  
Portland, OR 97207  
(503) 248-9985

*Handicapping Conditions Served:* Tinnitus.

*Users Served:* Disabled persons, health care professionals.

*The Organization:* The American Tinnitus Association (ATA) was founded to conduct and support research and educational activities relating to the cure of tinnitus and other defects or diseases of the ear. Tinnitus is the subjective experience of hearing a sound, a ringing, or a noise when no such external physical sound is present. The ATA provides information and referral and counseling services to persons affected with tinnitus. Additionally, information and research support is provided for professionals in the field of tinnitus. While the ATA has no official chapters, it offers information and assistance to about 140 tinnitus self-help groups across the country.

*Information Services:* The ATA has available several brochures about tinnitus and the Association. The ATA NEWSLETTER, a quarterly publication, includes timely articles and research reports about tinnitus. Also available for sale is Tinnitus: Proceedings of the 2nd International Tinnitus Seminar, a compilation of scientific papers. The ATA can provide a bibliography on tinnitus and statistical data on tinnitus patient characteristics, as well as public service announcements about this condition. Some material is available in Spanish; occasionally materials can be translated upon request. There is a nominal fee for most services and products.

Referrals for patients seeking help for tinnitus can be made to about 700 professionals in the United States and Canada. The ATA also sponsors workshop courses for hearing professionals.

**American Veterans of World War II, Korea, and  
Vietnam (AMVETS)**  
4647 Forbes Boulevard  
Lanham, MD 20706  
(301) 459-9600

*Handicapping Conditions Served:* All handicaps.

*The Organization:* AMVETS is a service organization for veterans, including handicapped veterans. The organization operates at national, state and local levels with 1400 local posts across the country. Its main concerns for handicapped veterans are veterans benefits--education, rehabilitation and employment--and legislation affecting the handicapped. A legislative staff in Washington keeps abreast of all new legislation affecting veterans and the handicapped, and maintains a close liaison with Congress. Individual advocacy is provided nationwide through a network of service offices located at regional offices of the Veterans Administration (VA).

*Information Services:* Although AMVETS is a membership organization, information and direct services are available to any veteran or dependents of veterans. AMVETS' primary effort is at the state and local levels, through service officers and accredited representatives. The officers and representatives offer counsel, information and referrals in the areas of education, rehabilitation and employment. They act as the veteran's initial contact in obtaining these benefits, and they refer him or her to the appropriate government agency. They will appeal individual cases before an agency such as the VA if a veteran fails to get his or her rightful benefits. At the post level, AMVETS members visit hospitalized veterans to provide whatever lay assistance they can for the patient's rehabilitation. Professional referrals and information about aids, equipment and prosthetic devices can be obtained from most service officers and post representatives, but the emphasis of each local service varies. The AMVETS newsletter includes reports on newly enacted and pending relevant legislation. For information, contact AMVETS at the above address, or an AMVETS service office at a regional VA office.

**The Amyotrophic Lateral Sclerosis Association (ALSA)**  
**15300 Ventura Boulevard**  
**Suite 315**  
**Sherman Oaks, CA 91403**

**185 Madison Avenue**  
**New York, NY 10016**  
**(212) 679-4016**

*Handicapping Conditions Served:* Amyotrophic lateral sclerosis (ALS), Lou Gehrig's disease.

*Users Served:* Disabled persons, physicians, physical therapists, speech therapists, neurological specialists.

*The Organization:* The Amyotrophic Lateral Sclerosis Association (ALSA) was established in 1984 through the merger of the former National ALS Foundation and the ALS Society of America. ALSA was formed to help ALS families live with the disease more effectively, to educate the public about the nature of ALS and to foster medical research on its cause and cure. ALS is a progressive, usually fatal disorder that attacks the body's nerves and muscles. ALSA carries on an extensive public information program nationwide to locate ALS patients and provide helpful information. Ten chapters nationwide support the psychological needs of families through peer counseling and make referrals to medical facilities for treatment and therapy for ALS patients. The Association supports four ALS Clinical Services Centers

research.

*Information Services:* Publications include Home Care for the Patient With Amyotrophic Lateral Sclerosis, also available in Spanish, and Why Didn't Somebody Tell Me About These Things?, a directory of information, aids and other topics of interest to the ALS patient. A wide range of pamphlets includes information on patient-family services, health insurance plans, breathing exercises, communication systems and devices, emergency treatment and support systems, as well as reports and evaluations of current research. A quarterly publication, The ALS Association Newsletter, reports on current experimental research developments, patient news, and activities of ALSA and its chapters. News bulletins are issued to members, if particularly newsworthy events occur between issues of the newsletter. Professionals in the field, as well as patients and their families, are encouraged to use ALSA as a clearinghouse of information on the management of ALS. There is no charge for information; ALS clinics may charge patients for specific services.

**Arthritis Foundation**  
**1314 Spring Street, NW**  
**Atlanta, GA 30309**  
**(404) 872-7100**

*Handicapping Conditions Served:* Arthritis, rheumatic diseases.

*Users Served:* Persons with rheumatic diseases and their families, health care professionals.

*The Organization:* The Arthritis Foundation is a national voluntary health association committed to finding the cause, prevention and cure for arthritis and other rheumatic diseases. Its programs include support for scientific research, training specialists, public information and education, and help within the community for people who have rheumatic diseases. The 71 local chapters and divisions of the Foundation provide basic information as well as assistance in locating treatment specialists, clinics and other agencies to help with physical, financial and emotional problems caused by arthritis. The chapters support a variety of local services, including information and education programs, support groups, arthritis clinics, home care programs and rehabilitation services.

*Information Services:* The Foundation disseminates information about new drugs and therapies to its chapters and to professionals in the arthritis treatment field. A variety of lay and professional pamphlets are available from the Foundation's local chapters, including information on specific forms of arthritis, various treatments, and solutions to physical and emotional problems associated with arthritis. Some materials are available in Spanish. Chapters maintain lists of medical and community services and make referrals upon request. The Foundation holds national and regional scientific meetings and continuing community education programs to advise local physicians of the latest clinical advances.

4156 Library Road  
Pittsburgh, PA 15234  
(412) 341-1515  
(412) 341-8077

*Handicapping Conditions Served:* All learning disabilities.

*Users Served:* Disabled persons, parents, teachers.

*The Organization:* The Association for Children and Adults with Learning Disabilities is a membership organization for professionals, adults with learning disabilities, and parents of children with learning disabilities. The national ACLD office provides general information about learning disabilities, while the 800 local chapters provide referrals to physicians and treatment centers. One of the prime functions of the national ACLD is the advocacy of educational and rehabilitative legislation affecting learning disabled persons. The ACLD conducts its own research into the link between juvenile delinquency and learning disabilities. With its state affiliates, ACLD works directly with school systems on early identification and diagnosis, as well as remediation in resource and special classroom situations. Direct services, such as parent counseling, nursery school, and day camps are provided by many of the local chapters; no direct services are available at the national level.

*Information Services:* Through state and national conferences, the ACLD distributes information on new technology for teaching learning disabled persons. For these meetings, ACLD gathers outstanding professionals to speak and answer questions concerning the nature of learning disabilities and the education available to learning disabled persons. Pamphlets and scientific reprints are available at no cost. National lists of colleges, private schools, and summer camps with facilities for learning disabled persons are compiled and updated by the national organization. The ACLD newsletter covers clinical advancements and legislative developments affecting learning disabled persons. A bibliography of more than 400 professional and lay publications on learning disabilities is available.

**Association for Persons with Severe Handicaps (TASH)**  
7010 Roosevelt Way, NE  
Seattle, WA 98115  
(206) 523-8446

*Handicapping Conditions Served:* Severe physical handicaps and profound mental retardation.

*Users Served:* Parents, administrators, teachers, medical personnel, researchers, speech pathologists, occupational and physical therapists.

*The Organization:* Formerly the American Association for the Education of the Severely/Profoundly Handicapped, the organization was founded in 1974 to respond to changes in legislation affecting persons with handicaps as well as to address the need for quality education and services for individuals experiencing severe and profound handicapping conditions. As reflected in the name change, the organization has expanded its range of concerns to include all services to individuals with severe and profound handicaps and is no longer limited to education. An international membership of over 600 includes parents and professionals. TASH advocates comprehensive, high quality, integrated

expertise; and supports those actively making the difference in quality education and services a reality.

TASH chapters are being chartered at local levels to facilitate increased involvement in local concerns. TASH has chartered or is developing chapters in 33 states. TASH chapters are also located in several Canadian provinces. New TASH chapters are continually being formed. A membership fee is charged.

*Information Service:* TASH publishes a monthly Newsletter and a quarterly Journal containing articles on new research trends and practices in services to individuals experiencing severe and profound handicapping conditions. Additional publications include four volumes of Teaching the Severely Handicapped, which reports on current research and innovations, and Methods of Instruction with Severely Handicapped Students. Books, papers, reprints from past issues of the Journal and bibliographies are available on subjects such as vocational training, curricula, and working with families. A bibliography of special interest to parents of children with severe handicaps is available from TASH and includes reference materials on advocacy, recreation, and self-help skills development. Ongoing surveys include those on integrated public schools and parent needs. A publications and price list can be requested. TASH has a parent-to-parent network of communication. By maintaining lists of parents whose children experience severe and profound handicaps and who are involved in local parent support and advocacy groups, TASH is able to put inquirers in touch with parents with similar concerns. TASH also maintains a register of professional contact people who are available for assistance on specific problems of education, training of personnel, etc. Referrals to direct service providers, including schools, clinics and vocational rehabilitation services, are made by letter or phone. TASH also holds an annual conference.

**Association for Retarded Citizens of the United States (ARC)**  
**National Headquarters**  
**2501 Avenue J**  
**Arlington, TX 76006**  
**(817) 640-0204**

*Handicapping Conditions Served:* Mental retardation.

*Users Served:* Disabled persons, parents, teachers, professionals.

*The Organization:* The goals of the Association for Retarded Citizens (ARC) are to prevent mental retardation, find cures, assist mentally retarded persons in their daily living, and provide support for their families. ARC's Research and Program Services Department conducts and sponsors projects to improve conditions for persons with mental retardation. Areas of concern include: (1) research studies on prevention and cure; (2) training volunteers who work with mentally retarded persons; (3) developing demonstration models for educational, training, and residential facilities; (4) developing effective advocacy systems; and (5) furthering employment opportunities for mentally retarded persons.

ARC's 1300 state and local units provide a variety of direct services to mentally retarded persons including day care centers, sheltered workshops, preschool programs and transportation services. ARC works on the national, state, and local levels to communicate and interpret the needs of persons with mental retardation to the public and to government.



articles, which it uses to research specific questions or to compile bibliographies. ARC's own publications are extensive and include pamphlets, monographs, books, handbooks, audio-visuals related to parenting, child development, citizen advocacy, civil rights education, recreation, vocational rehabilitation, progress in research on prevention cures, prevention methods, and statistics. General pamphlets about mental retardation, Down's Syndrome, and the Association and its activities are also available. The Association publishes newsletters devoted to local ARC projects, research and legislative activities, provides technical assistance through a Bio-engineering Program and On-the-Job Training Program. ARC also provides access to ARCNET, an electronic mail network. A few of ARC's publications are available in Spanish. There is a nominal fee for publications. Information about direct services may be obtained by contacting a state or local ARC unit.

**Association of Birth Defect Children (ABDC)**  
**3526 Emerywood Lane**  
**Orlando, FL 32806**  
**(305) 859-2821**

*Handicapping Conditions Served:* Birth defects of all kinds, especially those caused by environmental agents.

*Users Served:* Disabled persons, parents, teachers, and health care professionals.

*The Organization:* The Association of Birth Defect Children (ABDC), formerly Association of Bendectin Children, was established in 1980 to provide information and support to families of children with birth defects of a nongenetic nature, caused by mother's exposure to drugs, chemicals, radiation, and other environmental agents. Families of children with genetically caused birth defects are not excluded from membership. The Association is developing a birth defects registry, which contains demographic and medical history from member families throughout the United States and Canada.

*Information Services:* The Association's inquiry response service is geared primarily for parents and people in the medical and health related professions. It makes referrals to organizations working with specific birth defects. The Association also publishes a quarterly newsletter.

**Asthma & Allergy Foundation of America (AAFA)**  
**1835 K Street, NW**  
**Suite P-900**  
**Washington, DC 20006**  
**(202) 293-2950**

*Handicapping Conditions Served:* Asthma and allergic diseases.

*Users Served:* Disabled persons, parents, teachers, allergists, primary care physicians, and respiratory therapists.

*The Organization:* The main goal of the Asthma & Allergy Foundation of America (AAFA) is to provide information and support to families of children with asthma and allergic diseases. The organization also provides technical assistance through a Bio-engineering Program and On-the-Job Training Program. AAFA also provides access to AAFA-Net, an electronic mail network. A few of AAFA's publications are available in Spanish. There is a nominal fee for publications. Information about direct services may be obtained by contacting a state or local AAFA unit.

and immunology, patient training education courses and conferences, publications and audio-visual aids, and national awareness programs. Asthma Care Training for Kids (ACT), a self-management education course for children 7-11 and parents is offered by over 50 certified local groups. Health fairs, free community conferences and workshops are presented by the 4 state chapters and 19 local chapters of AAFA. Local volunteers and medical advisors offer support and referral services via the chapters. AAFA also sponsors the Asthma Athlete of the Year competition, awarding six college scholarships from \$1000 to \$10,000 to outstanding high school seniors who excel in academics and athletics.

*Information Services:* AAFA responds to mail inquiries for general advice and resources. Pamphlets for patients and the public are available on asthma, hay fever, mold allergy, drug allergy, sinusitis, allergy in children, insect allergy, exercise and asthma, and the immune system. The Foundation publishes the bimonthly national newspaper, The Asthma & Allergy ADVANCE; Consumer Information Bulletins, as new facts become available; and the Allergy Encyclopedia, a complete medical guide in paperback. Audio-visual materials include: "Conquering Asthma and Allergies" (15-minute color documentary film about active teenagers with asthma and allergic diseases) and "Running Hard, Breathing Easy" (15-minute color documentary film about asthmatic Olympic sprinter Jeanette Bolden). These films are available to groups on free loan. There is no charge for general information but there is a nominal fee for newspaper subscription and for pamphlets.

**Blinded Veterans Association (BVA)**  
1735 DeSales Street, NW  
Washington, DC 20036  
(202) 347-4010

*Handicapping Conditions Served:* Blindness.

*Users Served:* Disabled persons, physicians, physical therapists.

*The Organization:* The Blinded Veterans Association is a membership organization for veterans blinded during or after their military service. Advocacy, assistance, and fellowship are the goals of the organization. Direct services are based on the one-to-one principle that a blind veteran can most effectively motivate another blind veteran. BVA's Field Service Program, partially funded by the Veteran's Administration (VA), is carried out by field representatives, themselves blind, who visit blind veterans who have not been rehabilitated. They recommend rehabilitation centers, offer counseling in the areas of compensation, pensions, schooling, and the use of prosthetic aids and equipment, and counsel the veteran's family. BVA's Outreach Employment Program, partially funded by the Department of Labor, tries to convince employers, through public service advertising and direct contact, to give job opportunities to the blind veteran. BVA representatives assist the blind veteran by contacting prospective employers, and helping him to prepare resumes and job applications. They also offer counseling in job discrimination cases. BVA has 40 state groups whose volunteer members help to provide the organization's direct services.

*Information Services:* BVA publishes a bimonthly newsletter, BVA BULLETIN, which is sent free to all blinded veterans for whom current addresses are available, whether or not they are BVA members. It is also sent to many professionals in the field of blindness. A soundsheet version of the BULLETIN is sent to all members and associate members. The

Services about child health and information are available at no cost.  
describing the BVA and its principal programs are available at no cost.

**The Candlelighters Childhood Cancer Foundation**  
2025 Eye Street, NW  
Suite 1011  
Washington, DC 20006  
(202) 659-5136

*Handicapping Conditions Served:* Childhood/adolescent cancer.

*Users Served:* Parents, teachers, medical and social professionals who treat children/adolescents with cancer.

*The Organization:* The Candlelighters Foundation is an international organization of groups of parents who have or have had children with cancer. Believing that "it is better to light one candle than to curse the darkness," the organization works through its more than 225 chapters throughout the world to provide a variety of support services to families with a child cancer patient, including crisis lines, a parent-to-parent buddy system, and self-help groups. Individual chapters offer other services, which vary from group to group. The Foundation helps new chapters form and links existing chapters. Membership in Candlelighters is open to anyone interested in the control and cure of childhood cancer and in meeting the needs of families of children who have cancer, including professionals in the medical and social services fields.

Registered lobbyists at the metropolitan Washington, DC chapter testify at congressional hearings and coordinate the legislative action programs of local parent groups.

*Information Services:* The Foundation distributes bibliographies in the following areas: childhood cancer in general, materials for parents, and books for children at various age levels covering cancer and dying. An organization and information handbook is available to parents who want to start a new group. Candlelighters also sponsors conferences for parents, publishes a quarterly newsletter and a newsletter for teens, and serves as a clearinghouse on state and federal programs. Newsletters are free; there is a nominal charge for other publications. The Foundation operates on a grant from the National Office of the American Cancer Society, Inc. and tax exempt donations.

**Center on Human Policy**  
Syracuse University  
406 Huntington Hall  
Syracuse, NY 13210  
(315) 423-3851

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons, parents, professionals.

*The Organization:* The Center on Human Policy is an advocacy and research organization

Center provides consumers with information regarding legal rights and strategies for change. It provides consultation to public schools and other agencies on the integration of handicapped persons into the community.

**Consumers Organization for the Hearing Impaired, Inc. (COHI)**  
**c/o National Association for Hearing and Speech Action**  
**10801 Rockville Pike**  
**Rockville, MD 20852**  
**(800) 638-8255**

*Handicapping Conditions Served:* Hearing impairments.

*Users Served:* Disabled persons.

*The Organization:* The Consumers Organization for the Hearing Impaired (COHI) was formed in December 1977 by the Washington Area Group for Hard of Hearing and the Organization for Use of the Telephone. Its purpose is to organize the diverse groups of hearing impaired people--workers, students, professionals, homemakers, parents--to act as the national voice of the hard of hearing on consumer issues. One of the immediate objectives of the organization is to assure the presence of amplification systems in such facilities as auditoriums, university classrooms, theaters, movies and meeting rooms in public and private buildings. Long-range goals include promoting: (1) the modification of all public telephones for hearing aid wearers; (2) research in the fields of hearing disorders and hearing aids and devices; and (3) Federal and state financial assistance for rehabilitative services and aids for the hearing impaired.

*Information Services:* COHI has organizational, membership information and detailed information sheets explaining how consumers can assemble their own personal communications systems, how organizations can establish Assistive Listening Devices Centers and related material, available free upon request.

**Cooley's Anemia Foundation, Inc.**  
**105 East 22nd Street**  
**Suite 911**  
**New York, NY 10010**  
**(212) 598-0911**  
**(800) 221-3571**  
**(800) 522-7222 (NY)**

*Handicapping Conditions Served:* Cooley's anemia (thalassemia).

*Users Served:* All interested persons.

*The Organization:* The Foundation is committed to the eradication of this genetic blood disease which was once thought to occur only in those of Mediterranean heritage, and

can direct interested parties to free testing centers. An ongoing public education program alerts the at-risk population to the dangers of Cooley's anemia. The Foundation funds research projects here and abroad and conducts worldwide symposia on the disorder.

*Information Services:* The Foundation has a variety of printed materials on the disorder and on how to deal with it (films and audio-visuals, and a newsletter). It publishes materials from the symposia it sponsors and articles on the research progress of grant recipients. The Foundation also maintains a speakers' bureau.

**Cornelia deLange Syndrome Foundation (CdLS Foundation)**  
60 Dyer Avenue  
Collingsville, CT 06022  
(203) 693-0159

*Handicapping Conditions Served:* Cornelia deLange syndrome (CdLS).

*Users Served:* Disabled persons, parents, teachers, anyone interested in CdLS.

*The Organization:* Established in 1977, the Cornelia deLange Syndrome Foundation's purpose is to increase awareness about CdLS to encourage accurate and early diagnosis and to enable families and professionals to make responsible decisions about planning for present and future care of affected children. CdLS is a collection of specific medical signs and symptoms of unknown cause resulting in mental retardation, distinctive physical characteristics, delayed psychomotor development and feeding and behavior problems. The Foundation serves as a support system for children affected by CdLS and their families. Support for research on CdLS is a continuing focus of the Foundation.

*Information Services:* The Foundation publishes a directory of parents and interested persons and a pamphlet "Facts About CdLS." Reaching Out, a bimonthly newsletter for families and friends of people with CdLS, reports on Foundation activities, members research developments and treatment programs. A Spanish translation of the fact sheet is available.

**Council of Citizens with Low Vision (CCLV)**  
1315 Greenwood Avenue  
Kalamazoo, MI 49007  
(616) 381-9566

*Handicapping Conditions Served:* Visual impairment.

*Users Served:* Disabled persons, parents.

*The Organization:* The Council of Citizens with Low Vision (CCLV) was founded in 1978 to meet the particular needs of partially sighted persons. The basic purpose of the organization is to help partially sighted persons to be more independent and thus less dependent on costly public and private services. Toward that goal, the objectives of CCLV

expression of needs, preferences and interests of partially sighted persons; (3) educating the public, professionals and persons with low vision themselves as to their capabilities and special needs; (4) establishing outreach programs to ensure accessibility to services; (5) promoting research in various fields aimed at improving the lives of persons with usable residual vision; and (6) supporting the development of pre-service professional training programs to establish and expand low vision services. The five state chapters and one local chapter of CCLV conduct local programs based on specific needs in their respective areas. In addition to its annual conference with educational programs, CCLV actively promotes relevant legislation, statewide and nationally, and advocates for adequate signs on public facilities. The Council also provides scholarships for professionals who work in the field of low vision. CCLV is an affiliate of the American Council of the Blind (see separate entry).

*Information Services:* CCLV offers several pamphlets describing the organization and its mission and a bibliography, Understanding Low Vision. A quarterly newsletter reports on resources, new developments, research, chapter news and conferences. Materials are available in large print. A nominal membership fee is charged, which includes the newsletter subscription and a free subscription to the American Council of the Blind magazine, The Braille Forum. CCLV makes referrals to low vision services in local areas.

## **Cystic Fibrosis Foundation (CFF)** **6000 Executive Boulevard** **Rockville, MD 20852** **(301) 881-9130** **(800) FIGHT CF**

*Handicapping Conditions Served:* Cystic fibrosis (CF), chronic disease affecting pulmonary and digestive systems.

*Users Served:* Disabled persons, parents, teachers, researchers, doctors, nurses, therapists, caregivers.

*The Organization:* The Foundation was established in 1955 to find the means for prevention, control, and effective treatment of this chronic degenerative disease involving the lung, digestive organs, and other major organs of the body. Since there is yet no cure or long-term control of this most common genetic killer of children, CFF works through its chapters to alert the general public to symptoms of the disease so early diagnosis and treatment may prolong life of victims. The Foundation helps fund 126 treatment centers and makes grants to scientists, medical centers, and other organizations involved in research. Annual conferences are held for professionals in the field to present current research and plan future projects and guidelines for treatment. CFF belongs to the International Cystic Fibrosis (Mucoviscidosis) Association which includes organizations from 26 countries. Advocacy and public awareness campaigns are conducted locally as well as nationally; local seminars and meetings for patients and their families are held periodically. Because of progress in diagnosis and treatment, many CF patients are living into adulthood. As a result, there is a widespread growth of young adult groups through which patients share their experiences in coping with the disease.

*Information Services:* For professionals, publications include a Guide to Diagnosis and Management of Cystic Fibrosis, Medical Information, Guidelines for Health Personnel, and

Deaf Communications Institute (DCI)  
P.O. Box 247  
Fayville, MA 01745  
(617) 872-9406 (Voice and TDD)

*Handicapping Conditions Served:* Deafness, hearing impairment, deaf-blindness.

*Users Served:* Disabled persons, parents, teachers, professionals working with hearing-impaired persons, organizations of deaf persons and those serving deaf and hearing-impaired persons.

*The Organization:* Founded in 1980, Deaf Communications Institute (DCI) is a nonprofit organization for improved communications services for hearing-impaired persons. According to its by-laws, at least 51% of DCI's Board of Directors must be deaf. Through an international electronic mail service for deaf people called DCI Deafnet, the organization serves a group of deaf users, schools with programs for deaf students, and hearing people who have an interest in the deaf community. This service makes use of Telemail, a commercial electronic mail service owned by Telenet, a division of GTE (General Telephone and Electronics Corporation). International Communications Limited provides administration and management service of DCI Deafnet on GTE Telemail. Services offered by DCI Deafnet include electronic mail communications to individuals or groups of people, bulletin boards accessible to the entire membership which give announcements and news of interest to the deaf community, opportunities to meet others, and a forum for discussion. Electronic mail is a fast and efficient communication method, saving money on direct costs to individual members and convenient for picking up and sending messages, particularly when different time zones are involved.

DCI also operates the DEAF MESSENGER in the Boston community which is an experimental TDD-compatible electronic bulletin board accessed by TDD.

*Information Services:* Brochures are available describing the DCI organization and services offered. Anyone can join the DCI Deafnet electronic message service on GTE Telemail by completing the application form and paying an annual membership fee. Membership is open to any interested person. Rate sheets are available from International Communications Limited (the billing agent) through DCI Deafnet. Interested individuals can join DCI Deafnet without joining DCI Deafnet or Telemail.

DCI also provides technical consultation on telecommunications to groups of deaf people and gives testimony at government hearings.

Washington, DC 20018  
(202) 635-2050 (Voice and TDD)  
(202) 635-2433 (Voice and TDD)  
(202) 636-8330 (Voice and TDD)

*Handicapping Conditions Served:* Deafness and hearing impairment.

*Users Served:* Disabled persons, parents, hospital administrators and staff, other health care professionals.

*The Organization:* Deafpride, Inc. is a nonprofit organization which works for the human rights of deaf people and their families by bringing together deaf and hearing persons, and providing opportunities for them to develop their potential as advocates. Deafpride assists groups to organize and work for change, in the District of Columbia and throughout the United States. Deafpride offers activities and programs in leadership/advocacy development; family life; bilingual studies/deaf culture; health services access; technical assistance, information and referral; and sign language programs. The organization also provides interpreting services and conducts workshops and in-service training for health services consumers and providers. Deafpride can design programs, conferences or workshops to meet the specific needs of a group or institution and can provide speakers and panelists from the deaf community.

*Information Services:* Deafpride has produced a brochure describing its services and a booklet on access to medical services for deaf patients. The Advocate is Deafpride's quarterly newsletter which covers news of the organization's activities and projects, conferences, resources, and other items of interest. Deafpride also publishes Perspectives and Options, a collection of position papers, as well as other policy/concept papers. There is a membership charge (includes newsletter subscription) and fees for training sessions, sign language classes and interpreting services.

**Disability Rights Center**  
**Suite 1124**  
**1346 Connecticut Avenue, NW**  
**Washington, DC 20036**  
**(202) 223-3304**

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons, attorneys.

*The Organization:* The Disability Rights Center was established in 1976 to advocate for the rights of all disabled persons. At present, the Center is primarily involved in monitoring and seeking ways to strengthen the Federal agencies' affirmative action programs for the employment of disabled persons, as required by Section 501 of the Rehabilitation Act of 1973 and Section 403 of the Vietnam Era Veterans' Readjustment Assistance Act of 1974.

*Information Services:* The Center disseminates copies of research reports and proposals for change. Research into medical devices resulted in two publications: Medical Devices and Equipment for the Disabled and Consumer Warranty Law: Your Rights and How to Enforce Them. The Center also provides information on the Americans with Disabilities Act of 1990.



**Disability Rights Education and Defense Fund, Inc. (DREDF)**  
2212 6th Street  
Berkeley, CA 94710  
(415) 644-2555 (Voice)  
(415) 644-2629 (TDD)

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons and their families, organizations concerned with disabled persons, attorneys, legislators.

*The Organization:* DREDF, founded in 1979, is a national nonprofit organization primarily by disabled persons to achieve the goals of the disability rights movement. It monitors legislative and educational efforts and conducts training and research programs. DREDF has been very active in the training of disabled persons and their families in the application of their rights under Section 504 of the Rehabilitation Act of 1973. Recently, it organized a national effort to prevent deregulation of Section 504. DREDF conducted a study on the educational experiences of disabled females. More than 185,000 disabled women, girls and their parents were contacted to ascertain the level of treatment in education, employment, health, and social services. An executive summary of the study is available free of charge from the above address.

*Information Services:* DREDF offers concise and up-to-date information on civil rights for disabled persons to attorneys, federal agencies, legislators and their staffs. The Disability Rights Review, the organization's free quarterly newsletter, reports on legislative and judicial activities affecting disability rights. The review is distributed to disabled persons, parents, concerned organizations, attorneys and legislators.

**Disabled American Veterans (DAV)**  
P.O. Box 14301  
Cincinnati, OH 45214  
(606) 441-7300

*Handicapping Conditions Served:* Service-connected disabilities of veterans of all wars as well as special readjustment needs among Vietnam era veterans.

*Users Served:* Disabled persons, VA health care personnel.

*The Organization:* The DAV was formed following World War I as a self-help group for veterans with service-connected disabilities. The 1,000,000-member nonprofit association exists solely to serve disabled veterans and their families. There are 51 state departments, 2,760 local chapters and 1850 auxiliary units across the country. The DAV advocates and monitors legislation affecting the entire range of benefits for service-connected disabled veterans, including disability compensation, health care, pension, employment, vocational rehabilitation, death benefits, etc. Expert counseling and claims representation is provided to disabled veterans and their families at no cost by 270 DAV National Service Officers.

(NSOs) located in 67 cities in 49 states and Puerto Rico. DAV NSO's act as attorneys-in-fact, representing clients before the VA, Social Security Administration, Labor Department, HHS, and other government agencies. Since 1973, the DAV has sent Field Service Units to rural and suburban areas to serve veterans and families living some distance from a DAV office. The DAV has several programs aimed at unique problems in specific groups of veterans. These include Veterans of the Vietnam era, aging veterans, Native Americans and incarcerated veterans and others. The DAV provides disaster and emergency relief for disabled veterans and scholarships for children of needy disabled veterans. It also advocates local employment programs and removal of architectural and other barriers to the handicapped.

*Information Services:* A monthly news magazine covers veterans' benefits, including VA health care and veterans' legislation. It is also available on cassette. General inquiries concerning rights and benefits earned by disabled veterans should be sent to the above address. Requests for assistance with benefit claims should be sent to DAV National Service Department, 807 Maine Avenue, SW, Washington, DC 20024. DAV services are provided at no cost to veterans and their families.

**Dysautonomia Foundation**  
**370 Lexington Avenue**  
**New York, NY 10017**  
**(212) 889-5222**

*Handicapping Conditions Served:* Familial dysautonomia.

*Users Served:* Parents, physicians.

*The Organization:* Established in 1951 by parents of affected children, the Foundation now has 16 chapters in the U.S., Canada, Great Britain and Israel which raise funds for research into dysautonomia and provide information on this genetic disorder to the medical community and patients' families. The condition affects the autonomic (involuntary) nervous system and to a lesser extent the central nervous system, with a variety of symptoms. Confined to children of Eastern European Jewish ancestry, familial dysautonomia is a rare and often misdiagnosed disease; therefore education of pediatricians and parents in early detection and care is a primary concern. The Foundation maintains a Dysautonomia Treatment and Evaluation Center at New York University Medical Center for the benefit of patients and their physicians. A national medical symposium on the disorder is held annually for research scientists, clinicians and health care professionals.

*Information Services:* A variety of printed material is available without cost, including handbooks on nursing and family care of patients, reprints of articles from both professional and lay publications, bibliographies, fact sheets and brochures on the disease. Lists of local chapters, schools and camps familiar with the disorder, and names of physicians experienced in treating patients with the disorder can also be requested.

**Epidermolysis Bullosa (D.E.B.R.A.)**  
**Kings County Hospital Center**  
**451 Clarkson Avenue**  
**Building E**  
**6th Floor**  
**Room E6-101**  
**Brooklyn, NY 11203**  
**(718) 774-8700**

*Handicapping Conditions Served:* All forms of epidermolysis bullosa (EB).

*Users Served:* Parents, physicians, nurses, social workers, geneticists.

*The Organization:* D.E.B.R.A. was established in 1979 by a small number of parents of children with EB to provide an information and support network for patients and their families. One of D.E.B.R.A.'s primary goals is to encourage and support research into the causes, treatment, and cure of this little understood genetic skin disorder, which leads to localized or widespread blistering. Referrals are made to physicians, surgeons and other affected individuals.

*Information Services:* The Association responds to inquiries from patients, their families, and the general public, with information packets on the nature of EB, research information, and Association activities. D.E.B.R.A.'s periodic newsletter (samples are free upon request) reports on research findings, local conferences and workshops, and gives practical problem-solving advice for patients and their family members. There is a suggested membership fee, but any donation is acceptable. Most materials are free. The Association assists families in locating local sources of medical, social, and genetic counseling. D.E.B.R.A. maintains files of medical information provided to physicians and other health professionals concerning EB and its treatment, and is in the process of establishing a registry of EB patients. The organization also sponsors seminars and workshops for EB families and health professionals.

**Epilepsy Foundation of America (EFA)**  
**4351 Garden City Drive**  
**Suite 406**  
**Landover, MD 20785**  
**(301) 459-3700**

*Handicapping Conditions Served:* Epilepsy and seizure disorders.

*Users Served:* Disabled persons and their families, teachers, health care professionals.

*The Organization:* The Epilepsy Foundation of America (EFA) is a national, voluntary organization dedicated to the prevention and control of epilepsy and its consequences, and to helping persons with epilepsy, their families and other concerned individuals overcome the problems associated with this condition. EFA and its 84 affiliated local groups provide a variety of services and programs for the person with epilepsy. EFA sponsors a number of special projects, such as: (1) School Alert, designed to improve school environments for children with epilepsy by providing materials to help students, teachers and other school personnel understand the condition better; (2) National Epilepsy Library and Resource Center, which provides information and materials to individuals and groups; (3) National Epilepsy Research Fund, which provides grants to researchers; (4) National Epilepsy Registry, which provides information on the prevalence and distribution of epilepsy in the United States; (5) National Epilepsy Council, which provides information on the legal and social aspects of epilepsy; (6) National Epilepsy Task Force, which provides information on the medical and social aspects of epilepsy; (7) National Epilepsy Council on Education, which provides information on the educational aspects of epilepsy; (8) National Epilepsy Council on Employment, which provides information on the employment aspects of epilepsy; (9) National Epilepsy Council on Insurance, which provides information on the insurance aspects of epilepsy; (10) National Epilepsy Council on Transportation, which provides information on the transportation aspects of epilepsy; (11) National Epilepsy Council on Housing, which provides information on the housing aspects of epilepsy; (12) National Epilepsy Council on Recreation, which provides information on the recreation aspects of epilepsy; (13) National Epilepsy Council on Social Services, which provides information on the social services aspects of epilepsy; (14) National Epilepsy Council on Mental Health, which provides information on the mental health aspects of epilepsy; (15) National Epilepsy Council on Substance Abuse, which provides information on the substance abuse aspects of epilepsy; (16) National Epilepsy Council on Alcoholism, which provides information on the alcoholism aspects of epilepsy; (17) National Epilepsy Council on Smoking, which provides information on the smoking aspects of epilepsy; (18) National Epilepsy Council on Nutrition, which provides information on the nutrition aspects of epilepsy; (19) National Epilepsy Council on Exercise, which provides information on the exercise aspects of epilepsy; (20) National Epilepsy Council on Safety, which provides information on the safety aspects of epilepsy; (21) National Epilepsy Council on First Aid, which provides information on the first aid aspects of epilepsy; (22) National Epilepsy Council on Emergency Services, which provides information on the emergency services aspects of epilepsy; (23) National Epilepsy Council on Legal Services, which provides information on the legal services aspects of epilepsy; (24) National Epilepsy Council on Financial Services, which provides information on the financial services aspects of epilepsy; (25) National Epilepsy Council on Insurance Services, which provides information on the insurance services aspects of epilepsy; (26) National Epilepsy Council on Transportation Services, which provides information on the transportation services aspects of epilepsy; (27) National Epilepsy Council on Housing Services, which provides information on the housing services aspects of epilepsy; (28) National Epilepsy Council on Recreation Services, which provides information on the recreation services aspects of epilepsy; (29) National Epilepsy Council on Social Services, which provides information on the social services aspects of epilepsy; (30) National Epilepsy Council on Mental Health Services, which provides information on the mental health services aspects of epilepsy; (31) National Epilepsy Council on Substance Abuse Services, which provides information on the substance abuse services aspects of epilepsy; (32) National Epilepsy Council on Alcoholism Services, which provides information on the alcoholism services aspects of epilepsy; (33) National Epilepsy Council on Smoking Services, which provides information on the smoking services aspects of epilepsy; (34) National Epilepsy Council on Nutrition Services, which provides information on the nutrition services aspects of epilepsy; 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(99) National Epilepsy Council on Exercise Services, which provides information on the exercise services aspects of epilepsy; (100) National Epilepsy Council on Safety Services, which provides information on the safety services aspects of epilepsy.

**Information Services:** EFA provides information on epilepsy and its consequences to any person or group requesting it. Areas include: (1) information on epilepsy for the patient, his family and friends; (2) educational material to individuals and groups dealing with people with seizure disorders; (3) information on employment, including vocational rehabilitation and training, rights, hiring and insurance regulations, special programs, and the particular needs of some people with epilepsy whose seizures are not fully controlled; (4) specific information on the rights of persons with epilepsy as guaranteed by Federal and state statutes; (5) housing information (mostly about discrimination and alternative living arrangements, such as group homes); (6) transportation information, including Federal and state driving regulations; (7) health service information, including prevention, diagnosis, treatment, rehabilitation, and maintenance; (8) information on economic, social and psychological services, such as disability benefits and supplemental security income, recreational services, and individual and group counseling programs; (9) information on the latest research into the causes, treatment and prevention of seizures; and (10) information on Federal and state programs that affect people with epilepsy. Many local affiliates offer similar information services. Some are affiliated with epilepsy clinics or work closely with them. Information on local epilepsy clinics is available from EFA. EFA publishes pamphlets, bibliographies, reprints, books, cassettes, slides, films and a newsletter. The newsletter, National Spokesman, is published ten times per year, covering news and developments in research, legal issues, affiliate activities, national news and self-help. Single copies of literature are provided free; there is a charge for bulk orders and rentals and sales charges for films and audio-visuals. A limited number of brochures have been prepared in braille. A few general brochures are available in Spanish; some affiliates offer materials in other languages as well.

**The Family Survival Project (FSP)**  
1736 Divisadero Street  
San Francisco, CA 94115  
(415) 921-5400

**Handicapping Conditions Served:** Adults with chronic brain disorder.

**Users Served:** Disabled persons, family caregivers, teachers and professionals.

**The Organization:** The Family Survival Project is a nonprofit organization founded to assist families of adults who have been stricken with chronic or progressive brain disorders (stroke, head injury, Alzheimer's disease, senile dementia, etc.). Its goals include public advocacy for those suffering financial and emotional distress, direct services to families (mostly in California), and the national distribution of information on the care of brain-damaged persons. Through its publications and national conferences, the FSP coordinates and provides specialized training for professionals, primary care givers, and other interested persons to help them understand current research activities and treatment approaches.

**Information Services:** Information for families and professionals is available on FSP study results, workshop materials, and on adult brain disorders. Information on stroke and Alzheimer's disease is available in Spanish. Available publications include Family Survival Handbook: A Guide to the Financial, Legal, and Social Problems of Brain-Damaged Adults, single copies free; and FSP Training Packet: Learning to Survive, for which there is a fee.

Information about new training activities, new publications, and other services is contained in Update, the FSP's quarterly newsletter. The FSP offers training workshops on management, diagnosis and treatment, long-term care, legal and financial issues, and topics upon request on a fee basis.

The Project also maintains a speakers' bureau for media interviews, community and public hearings, etc. Technical assistance in establishing support groups, development programs, and writing social policy is available to groups and organizations on a fee basis.

**Foundation for Children with Learning Disabilities (FCLD)**  
P.O. Box 2929  
Grand Central Station  
New York, NY 10163  
(212) 687-7211

*Handicapping Conditions Served:* Learning disabilities.

*Users Served:* Disabled persons, parents, teachers, pediatricians, therapists, psychologists, legislators.

*The Organization:* The Foundation for Children with Learning Disabilities (FCLD), established in 1977, is primarily a public awareness and funding organization. Its public awareness is accomplished through distribution of Foundation publications, public service radio and television spots.

The Foundation funds innovative programs in the learning disabilities area which have limited or no access to support from alternative means of funding. Projects which are community based and can serve as demonstration models receive high priority. The Foundation funds programs that emphasize volunteer involvement. Approximately one million dollars have been given to model programs which help LD children in schools, camps, recreation centers, museums, and for parent/teacher training. Through recent grants, FCLD has led national efforts to: (1) encourage public library systems to become resource centers for learning disabled children; and (2) increase public awareness of judiciary and police personnel, attorneys, and the police about the now established link between learning disabilities and juvenile delinquent behavior.

*Information Services:* FCLD has two publications which are a public service and are available for only postage and handling charges. Their World is an annual magazine which contains life stories for and about families with learning disabled children. It is the most comprehensive publication for lay persons in the LD field. The FCLD Guide for Parents of Children with Learning Disabilities contains state-by-state listings of schools, insurance companies, and agencies which assist LD children. The Foundation will provide ordering information upon request.

**Friedreich's Ataxia Group in America, Inc. (FAGA)**  
P.O. Box 11116  
Oakland, CA 94611  
(415) 655-2222

is characterized by a slow, progressive loss of function of those parts of the nervous system that control coordination, curvatures of the feet and spine, and heart abnormalities. Diabetes and problems with vision and hearing may also develop. FAGA focuses on the physical and emotional well-being of individuals and their families, support of research into the cause and treatment of FA and education about this disorder. Information and support is provided through 22 state chapters.

*Information Services:* FAGA publishes a newsletter three times a year to share information about members, chapter activities, research developments, legislation and related topics. The group also publishes a brochure explaining FA. Referrals are made to the Muscular Dystrophy Association, which offers free clinical services for people with FA, including the provision of orthopedic aids. Membership information (no dues) may be obtained by writing to the organization.

**Gaucher's Disease Registry (GDR)**  
**4418 E Chapman**  
**No. 139**  
**Orange, CA 92669**  
**(714) 532-2212**

*Handicapping Conditions Served:* Gaucher's disease (all types).

*Users Served:* Disabled persons, parents, physicians, geneticists.

*The Organization:* Gaucher's Disease Registry (GDR) is a self-help group established in 1980 to locate affected persons and to disseminate information about this genetic disease which causes enlargement of the liver and spleen and deterioration of the bones.

*Information Services:* GDR acts as a clearinghouse of information on research, symptoms and day-to-day management of the disease. A bimonthly newsletter, Gaucher's Disease Registry Newsletter, is sent to all members and interested persons. It contains material relevant to GD, such as health news, disability aids, research developments and activities of support groups. Fact sheets and general materials are available to anyone requesting information. GDR can make referrals to physicians and genetics clinics.

**Gazette International Networking Institute (G.I.N.I.)**  
**4502 Maryland Avenue**  
**St. Louis, MO 63108**  
**(314) 361-0475**

*Handicapping Conditions Served:* Physical disabilities.

*Users Served:* Disabled persons, physicians, physical therapists, occupational therapists, respiratory therapists, social workers, nurses, rehabilitation counselors.

international journal for people with severe disabilities. Other objectives of the organization are to reach, inform, encourage and dignify people with disabilities and promote a positive attitude toward disabled individuals. G.I.N.I. maintains an international clearinghouse for dissemination of information to disabled individuals and health professionals, with special emphasis on polio survivors, ventilator-assisted living, spinal cord injury, adaptive equipment and independent living. Computerization of clearinghouse information is anticipated. G.I.N.I. also convenes international conferences on post-polio problems and independent living which bring together physicians and disabled individuals on an equal basis. Membership is also available in the International Polio Network through G.I.N.I. for an annual fee. Membership includes a subscription to Polio Network News.

*Information Services:* Annually, G.I.N.I. publishes the Rehabilitation Gazette which is written by individuals with physical disabilities and focuses on independent living for physically disabled persons, especially polio survivors, spinal cord injured, ventilator users and others with neuromuscular diseases and disabilities. The Institute has recently begun a newsletter, to be published quarterly, which covers G.I.N.I. activities, polio support groups and items of interest to ventilator users. Other publications include Handbook on the Effects of Poliomyelitis for Physicians and Survivors, Proceedings, 2nd International Polio Conference, 1983, and Proceedings, 3rd International Polio Independent Living Conference, 1985. There is a charge for most publications. G.I.N.I. subscribes to journals in English, French, Spanish, Japanese, Arabic, German and Portuguese and can provide information in these languages, as necessary.

Referrals are made to individuals with the same disability, physicians, hospitals, agencies, independent living centers, and libraries. The G.I.N.I. library contains case histories which provide evidence that ventilator users can live better and more inexpensively at home.

**Hemochromatosis Research Foundation, Inc. (HRF)**  
P.O. Box 8569  
Albany, NY 12208  
(518) 489-0972

*Handicapping Conditions Served:* Hemochromatosis (hereditary and acquired).

*Users Served:* Patients with hemochromatosis and their families, physicians and nurses, blood banks and genetic organizations.

*The Organization:* Hereditary hemochromatosis (HH) is a genetic disorder in which there is an increased absorption of dietary iron above body needs. Since the body has no way of ridding itself of excess iron once absorbed except by blood loss, iron accumulates in the liver, heart, pancreas and other hormonal glands, and joints causing serious complications, and, if undiagnosed and untreated, sometimes early death. Acquired hemochromatosis is secondary to a primary medical condition, such as chronic anemia and chronic liver disease. The goals of the Hemochromatosis Research Foundation, Inc. (HRF) include: (1) increase the awareness of the public and medical community of HH, its commonality, diagnosis and treatment; (2) encouraging routine use of screening tests by physicians; (3) promoting research aimed at identifying the genetic defect(s) causing the increased iron absorption; (4) understanding the toxic effects of iron; and (5) soliciting funds for screening, prevalence studies and research. HRF refers patients and families to clinics, hospitals and physicians.

include additional information on treatment monitoring and a bibliography of medical journals. Booklets are available in braille through the Library of Congress and the physician's booklet is available in Spanish. A quarterly newsletter, Hemochromatosis Awareness, provides an update on hereditary and acquired iron over-load, through case presentation, articles, news of research developments and a question and answer section. Information is free, but requests for booklets should be accompanied by a self-addressed and 39-cent stamped envelope.

**Human Growth Foundation (HGF)**  
**4720 Montgomery Lane**  
**Bethesda, MD 20814**  
**(301) 656-7540**

*Handicapping Conditions Served:* Growth retardation.

*Users Served:* Parents, pediatricians, researchers in the field of growth retardation.

*The Organization:* The members of the Human Growth Foundation (HGF) are parents of children with severe physical growth problems, and physicians and scientists specializing in the field of growth retardation. The Foundation supports research in endocrinology, and working with the National Pituitary Agency, tries to secure pituitary glands through donations. Pituitary glands are the only source of human growth hormone (HGH), which is often used in the treatment of growth retardation. Twenty local chapters of HGF provide opportunities for parents to share problems associated with their short-statured children.

*Information Services:* The national and local organizations provide parent and public educational materials about growth problems. Pamphlets on specific growth disorders, such as Turner's syndrome and achondroplasia, are available. Also offered are general brochures on problems in parenting a growth-retarded child, scientific developments, Foundation information, and how to become a pituitary gland donor. HGF makes referrals to physicians who specialize in growth retardation.

**Huntington's Disease Foundation of America, Inc. (HDFA)**  
**250 West 57th Street**  
**Suite 2016**  
**New York, NY 10107**  
**(212) 757-0443**

*Handicapping Conditions Served:* Huntington's disease (HD).

*Users Served:* Disabled persons and their families, health care professionals, researchers.

*The Organization:* HDFA (formerly the Committee to Combat Huntington's Disease) has 2 chapters and 15 branches in addition to a network of support groups. Goals are identification of HD families; education of the HD family, the general public, and the medical professional, with emphasis on increasing consumer awareness of HD; and a patient services program, coordinated with various community services, to assist families in meeting



*Information Services:* The Foundation maintains a roster of HD families and health care professionals interested in HD, which serves as a unique source of data for the researcher. It also cosponsors and supports workshops. Referral services are available for genetic counseling and other needs. A national hot line operates from 9 a.m. to 5 p.m. weekdays, and crisis intervention services are available at these hours. A wide variety of educational materials and reprints are available from HDFA, some of which are offered at no charge. In addition to a lending library of audio-visual materials designed for the professional and the general public, as well as media materials, it also has a lending library of general and scientific displays. Speakers are available, with advance notice, in areas where chapters are located.

**International Association of Laryngectomees (IAL)**  
**American Cancer Society (ACS)**  
90 Park Avenue  
New York, NY 10016  
(212) 371-2900

*Handicapping Conditions Served:* Laryngectomy.

*Users Served:* Disabled persons and their families, professionals.

*The Organization:* The International Association of Laryngectomees (IAL) (those whose larynxes have been surgically removed) is a coordinating organization of more than 330 laryngectomee clubs located in the U.S. and abroad. It is financially sponsored by the American Cancer Society (see separate entry). IAL club members are laryngectomees spouses, speech pathologists and speech therapists who provide rehabilitation (esophageal speech training), motivation and moral support to newly laryngectomized patients on a volunteer basis.

*Information Services:* IAL publishes brochures and fact sheets about speech training, speech devices, medical, nursing and family care of the laryngectomee, psychological problems of the laryngectomee, first aid and vocational adjustment problems. Reprints and professional papers are available on similar subjects of interest to the patient, his family and professionals. IAL's major publications include: (1) Annual Directory--which lists member clubs, meeting dates and places, availability of speech instruction, and local sources of supplies--from stoma covers, to artificial larynxes to medical, rehabilitation and teaching films; (2) Laryngectomized Speaker's Source Book, which includes information on cancer of the larynx, problems faced by laryngectomees, speech of the laryngectomee, speaking tips, rehabilitation needs, and information about the IAL; and (3) Registry of Laryngectomized Instructors of Esophageal Speech.

A quarterly newsletter reports on club activities. All materials may be obtained from AC national or local offices. IAL refers inquirers to speech therapists, but does not make medical referrals. The IAL holds an annual meeting and a speech institute in conjunction with it.

**1350 New York Avenue, NW  
Suite 500  
Washington, DC 20005  
(202) 393-1250**

*Handicapping Conditions Served:* Mental retardation.

*Users Served:* Organizations for mentally retarded persons, universities, and the general public.

*The Organization:* Established in 1946, the Foundation's purpose is to raise public awareness of medical ethical problems and to improve the quality of life for mentally retarded persons. To these ends the Foundation has funded research and clinical treatment centers at nine universities, instituted two centers for the study of medical ethics at Georgetown University and Harvard, underwritten fellowships in medical and nursing education for postgraduate study of medical ethics, and developed recreational programs including internships, family play programs, and the international Special Olympics Program for mentally retarded persons. Proposals for innovative demonstration models from agencies or individuals are considered for funding. Extensive public awareness campaigns are carried on through the media to improve understanding and acceptance of this population.

*Information Services:* Brochures describing the Special Olympics Program, the Let's Play to Grow Program for families, and the Community of Caring Program for adolescent mothers are available from the Foundation office. Films on the Special Olympics are available for TV or group use. Another group of films produced for education of health and other professionals includes such titles as "The Right to Survive," "The Right to Let Die," "The Right to Reproduce," and "Becky: The Value of a Life." There is a small rental or purchase fee charged for films; other information is free.

**Junior National Association of the Deaf (Jr. NAD)  
445 N. Pennsylvania  
Suite 804  
Indianapolis, IN 46204  
(317) 638-1715 (Voice and TDD)**

*Handicapping Conditions Served:* Deafness

*Users Served:* Deaf Students.

*The Organization:* Established in 1960 to develop leaders among young deaf students, Jr. NAD has 90 chapters in schools and programs at secondary and post-secondary levels throughout the country. Local and regional conferences are sponsored annually, while the national conference is sponsored biennially. Summer camp programs for students 8-13 and 14-19 are held every year. Awards for achievement in athletics, scholarship, writing, and citizenship are given to encourage leadership skills. Membership dues are \$5.00 per year.

*Information Services:* The Jr. NAD Newsletter is published monthly January through May. Brochures on summer camp and the Jr. NAD are available from the national office.

*Users Served:* Disabled persons, parents, teachers, and researchers.

*The Organization:* This organization's primary objective is to support and fund research, the treatment and cure of diabetes, mainly juvenile diabetes (also called insulin-dependent diabetes), which has its usual onset from infancy to the late thirties. JDF International awards grants and fellowships for specific research projects in diabetes and related areas, sponsors national media campaigns to inform the public about diabetes and to raise funds for research. Its 149 local chapters provide parent to parent counseling and self-help for newly diagnosed diabetics and their families. JDF International also has international affiliates.

*Information Services:* The Organization publishes free pamphlets and fact sheets about diabetes and insulin for the lay person. They include such titles as: What You Know About Juvenile Diabetes; Parent to Parent; Babies with Diabetes; Juvenile Diabetes Isn't Just for Kids; Having Children...A Guide for the Diabetic Woman; and What You Should Know About Insulin. A newsletter, Diabetes Countdown, is published for members. Local chapters hold public education meetings, maintain speaker bureaus, and provide referral to medical specialists and educational programs offered by hospitals and health departments. Some chapters have an information hot line.

**Leukemia Society of America**  
733 Third Avenue  
New York, NY 10017  
(212) 573-8484

*Handicapping Conditions Served:* Leukemia, the lymphomas, multiple myeloma, and Hodgkin's disease.

*Users Served:* Disabled persons, parents, physicians, nurses, social workers.

*The Organization:* The objectives of the Leukemia Society of America are to find a cure for leukemia, the lymphomas, multiple myeloma, and Hodgkin's disease, and to provide supplementary financial assistance to persons afflicted with those diseases. Research grants are provided to individuals investigating aspects of leukemia and related diseases. Society's 57 chapters administer patient aid programs, whereby outpatients can receive up to \$750 per year for drugs, radiation treatments, transfusions of blood and certain body components with related services, and transportation.

*Information Services:* The Society publishes pamphlets about leukemia, Hodgkin's disease, myelomas and the lymphomas. Some information is available in Spanish. Audio and video materials on what leukemia is and how persons may be affected by it are available to schools and community groups. Video and audio tapes from symposia are available to the professional. They deal with therapy and treatment of leukemia and virology, immunology, and differentiation. For the professional, chapters also offer symposia in conjunction with local medical facilities which emphasize new developments in treatment and main-

service to the professional and academic community, the Society maintains a bibliography of research conducted by other organizations and has a library of books and journals on leukemia and related diseases. The Society refers inquirers to leukemia centers throughout the world, and chapters provide information on possible sources of local financial aid. A bimonthly newsletter, Society News, reports on activities of the organization.

**Little People of America (LPA)**  
Box 633  
San Bruno, CA 94066  
(415) 589-0695

*Handicapping Conditions Served:* Dwarfism.

*Users Served:* Disabled persons, parents, professionals.

*The Organization:* Little People of America (LPA) was established in 1957 as a nationwide organization for dwarfs and their families to provide fellowship, the interchange of ideas, solutions to the problems unique to the little person, and moral support. A special membership division provides opportunities for information exchange and group support to parents of dwarfed children. Twelve district directors coordinate local activities, regional and local meetings and informal gatherings sponsored by over 30 local chapters throughout the country. LPA conducts national meetings annually. LPA works closely with adoption agencies throughout the U.S., attempting to place dwarfed children in the homes of dwarfed parents. In 1968, LPA established a foundation to raise funds for vocational training of little people and medical and scientific research on the causes and possible treatment of dwarfism.

*Information Services:* In addition to a bimonthly organizational newsletter, LP Today, LPA distributes printed material on equipment and aids, clothing, and social and vocational adjustment. Some brochures are available in Spanish. My Child Is a Dwarf is a pamphlet of special interest to parents. Materials are free to members; there is a mailing charge for nonmembers. LPA's medical board is used as a referral network to respond to medically related inquiries; general inquiries are sent to district directors for responses.

**Lowe's Syndrome Association (LSA)**  
222 Lincoln Street  
West Lafayette, IN 47906  
(317) 743-3634

*Handicapping Conditions Served:* Lowe's syndrome.

*Users Serves:* Parents and family members, physicians, physical, occupational and vision therapists, genetic counselors, social service professionals.

*The Organization:* Established in 1983, the Lowe's Syndrome Association (LSA) is an international, voluntary, nonprofit organization composed of parents, medical and educational professionals, friends, relatives and others interested in Lowe's syndrome. The

*Information Services:* The LSA provides pamphlets about Lowe's syndrome and the Association and a publications list to anyone who inquires. The organization also publishes a newsletter, On the Beam, which is sent to all members three times per year. The newsletter contains letters from parents and pictures of their children, medical and educational articles, recommended resources, news of the association and other items of interest. A membership fee is charged, which includes a subscription to the newsletter.

The LSA will refer parents and medical professionals to doctors who are experienced with Lowe's syndrome.

**Lupus Foundation of America, Inc.**  
4434 Covington Highway  
Decatur, GA 30035  
(404) 289-7453  
(800) 558-0121

*Handicapping Conditions Served:* Systemic lupus erythematosus.

*Users Served:* Disabled persons, parents, teachers, professionals.

*The Organization:* Incorporated in 1977, the Lupus Foundation of America is a federation of 16 state chapters, 78 local chapters, 138 affiliates and 3 foreign associates. Chapters and affiliates vary in size and scope of activities; some offer educational programs to nursing schools, hospital staffs and other organizations, while others fund fellowships and research grants to physicians who specialize in treatment of lupus. Many chapters conduct monthly open meetings with physicians, and publish newsletters and articles to alert physicians as well as the public to the symptoms of this often misdiagnosed disease.

*Information Services:* Bibliographies for professionals and patients, article reprints, and pamphlets explaining the disease are available. Some information is free; a nominal charge is made for selected pamphlets and books. Information is available in French and Spanish and the book The Sun is My Enemy is translated into Chinese. The Kansas City Chapter has a great deal of material in braille, available on request. LUPUS NEWS, a national paper, is published quarterly and includes information about the disease, research developments, and more. All of the large and most small chapters also publish papers six to ten times per year, focusing on information of local concern in addition to the broader topics of medical and research news. The national office has a list of physicians in foreign countries who treat lupus. Many local chapters and affiliates also maintain such lists for their area. Information and lists of local chapters may be requested from the Foundation.

**Mainstream, Inc.**  
1200 15th Street, NW  
Washington, DC 20005  
(202) 833-1136 (Voice and TDD)

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons, EEO officers, personnel managers, disability service providers.

*The Organization:* Mainstream, Inc. is a national nonprofit organization founded in 1975. Its purpose is to increase employment opportunities for disabled people by working with employers and the handicapped community to develop cost-effective solutions to problems inherent in the mainstreaming-into-the-workplace process. Mainstream offers information services and technical assistance on a consulting basis, in areas such as the design of affirmative action plans, development of in-house attitude and awareness training programs and evaluation of community-based recruiting sources. Mainstream has conducted numerous regional conferences to train its audience of employers, disabled people, educators, government officials and rehabilitation specialists on a variety of topics, including job analysis, reasonable accommodation, physical accessibility, legal concerns and interviewing and recruiting techniques. Since 1983, Mainstream has operated Project LINK, a national job development and placement model. LINK matches qualified applicants with available jobs in Washington, DC and Dallas, TX. These project sites serve as centralized applicant referral sources for employers.

*Information Services:* Mainstream has produced and disseminated many publications, including pamphlets on specific disabilities, medical standards in employment, insurance and section 503. Most information is available on cassette. A bimonthly newsletter, In the Mainstream, reports on programs, methods, organizations and resources effective in mainstreaming disabled people into the workplace in addition to analyses of relevant legislative, administrative and judicial activities. The Mainstream Information Network responds to inquiries on all handicap employment issues. Mainstream had also produced a manual for company trainers, Successful Mainstreaming of Disabled People into the Workplace. Publications and services can be purchased individually or on an annual subscription basis.

**March of Dimes Birth Defects Foundation (MOD)**  
**1275 Mamaroneck Avenue**  
**White Plains, NY 10605**  
**(914) 428-7100**

*Handicapping Conditions Served:* Congenital defects and genetic disorders.

*Users Served:* Disabled persons, parents, teachers, and physicians.

*The Organization:* To achieve its goals of preventing birth defects, the March of Dimes Birth Defects Foundation funds programs in basic and clinical research (including environmental reproductive hazards), medical services, professional and public education, and community services. Medical services have funded 85 clinical centers in the U.S. which practice genetic medicine and counseling. Satellite clinics provide genetic services for areas with limited medical resources. The MOD funds facilities providing intensive care services for sick newborns and follow-up studies of these infants after discharge. Emphasis now is being placed on early diagnosis and treatment of pregnant women with high risk conditions. Outreach clinics are being started in communities where prenatal care is unavailable.

*Information Services:* The March of Dimes funds programs through schools, churches

Through its Professional Education Publications Program, the March of Dimes transmits the latest scientific findings--in original articles and journal reprints--on birth defects to schools of medicine and nursing, university hospitals, medical centers, physicians, nurses and other health professionals. Also included in the publications program are: (1) the International Directory of Genetic Services, a listing of medical centers that provide genetic counseling and analyses of special genetic conditions; (2) the Birth Defects Atlas and Compendium which standardizes names and descriptions of 1,005 congenital anomalies, in four languages and (3) Genetics in Practice, a quarterly newsletter for health professionals.

The MOD serves as a clearinghouse for the exchange of incidence data generated in birth defect monitoring programs in 14 countries.

**Mental Health Law Project (MHLP)**  
2021 L Street, NW  
Suite 800  
Washington, DC 20036-4909  
(202) 467-5730

*Handicapping Conditions Served:* Mental and emotional disorders and developmental disabilities.

*Users Served:* Attorneys, disability organizations (parent/professional/client groups).

*The Organization:* Formed in 1972 as a nonprofit public organization, the Project is dedicated to law reform advocacy on behalf of people labeled mentally or developmentally disabled. Test case litigation is used to define, establish, and implement the rights of such persons. Landmark judicial decisions are followed with policy advocacy at the Federal level. Priority issues are preventing neglect and abuse of institutionalized mentally disabled people and generating adequate health and mental health care, education, housing, vocational and supportive services for mentally disabled people living in the community. MHLP also devotes some resources to protecting the civil rights of persons subject to civil commitment or procedures (e.g. ECT, psychotropic drugs). Regional training conferences on mental disability law have been cosponsored with the Practicing Law Institute. Advice on legal strategies for clients appearing before administrative agencies and legislative bodies is available; when appropriate, MHLP will represent protection and advocacy organizations before Federal agencies.

*Information Services:* MHLP offers backup assistance to attorneys and other advocates representing mentally handicapped clients. These services include model pleadings, legal citations and technical references, discussion of strategies, and comments on pleadings, draft legislation/regulations, assistance in using experts, provision of articles, memoranda, bibliographies, etc. In answer to inquiries from professionals and other interested persons, MHLP supplies general information about legal rights and makes referrals to attorneys. Publications include Legal Rights of Mentally Disabled Persons, a three volume course book which includes technical information about mental health and retardation issues, case law and legal analysis; and other books and reprints of articles by staff attorneys. MHLP's UPDATE is a bimonthly newsletter which offers a succinct overview of federal legislative, administrative and judicial developments affecting mentally disabled people. It is sent without charge to nonprofit organizations actively involved in the field.

and issues of concern. A nominal fee for duplication and mailing costs is charged for legal papers, bibliographies and other information.

**Muscular Dystrophy Association (MDA)**  
**810 Seventh Avenue**  
**New York, NY 10019**  
**(212) 586-0808**

*Handicapping Conditions Served:* Muscular dystrophy and related neuromuscular disorders.

*Users Served:* Individuals with neuromuscular diseases and their families.

*The Organization:* The Muscular Dystrophy Association (MDA) supports research into 40 neuromuscular disorders. It also provides medical care and other direct services to people with neuromuscular disorders through its 240 clinics and some 170 local chapters. MDA clinics provide diagnosis, physical therapy, medical care and counseling. Upon prescription MDA chapters provide payment for services including: physical, occupational, and respiratory therapies; orthopedic equipment; respiratory equipment; transportation; and flu shots. The chapters also sponsor recreational activities, such as summer camps, picnics, and outings. Some chapters organize self-help groups for people with neuromuscular diseases.

*Information Services:* MDA publishes brochures and audio-visual materials about neuromuscular diseases. Its quarterly magazine covers progress in research, legislation, and various MDA supported programs. Publications are free and available from MDA's national office or its chapters, many of which publish additional informative materials. Local chapters hold patient seminars which focus on available community, financial, educational and psychological programs. They also hold professional seminars on diagnosis, clinical management, and research.

**Myasthenia Gravis (MG) Foundation**  
**7-11 South Broadway**  
**Suite 304**  
**White Plains, NY 10601**  
**(914) 328-1717**

*Handicapping Conditions Served:* Myasthenia gravis.

*Users Served:* MG patients and family members, medical and scientific personnel.

*The Organization:* The Myasthenia Gravis (MG) Foundation is dedicated to the detection, treatment, and search for a cure of MG. In an effort to prevent misdiagnosis, promote public awareness and early detection, and publicize current treatment modalities, the Myasthenia Gravis Foundation offers educational materials to professionals and the public. Research grants and fellowships are awarded annually to medical students and physicians. The Foundation also sponsors annual scientific meetings and quinquennial international symposia for physicians and researchers; proceedings of the symposia (major state-of-the-art documents) are published and distributed to the medical community. Nationwide chapters



drug banks and recent research are available from the chapters. Publications for the patient and general public include Myasthenia Gravis--the Disease and a Case History, Facts About Myasthenia Gravis for Patients and Families, and MG and the MG Foundation. A medical emergency ID card is also available. Slide/sound presentations are loaned by chapters to community groups for showings. Materials for medical professionals are available in English or Spanish editions and include a Manual on diagnosis and management for physicians and a companion Manual for nurses.

**National Alliance for the Mentally Ill (National AMI)**  
1901 N. Ft. Myer Drive  
#500  
Arlington, VA 22209  
(703) 524-7600

*Handicapping Conditions Served:* Mental illness.

*Users Served:* Disabled persons and their families.

*The Organization:* The National Alliance for the Mentally Ill (National AMI) was founded in 1979 at a conference of independent self-help organizations concerned with severe and chronic mentally ill individuals both in institutions and in community-based settings. The organization promotes public education on mental illness; consumer advocacy at the local, state and national levels to enact new and remedial legislation and funding to provide and strengthen services and programs for the chronic mentally ill; and research in the neurosciences and clinical sciences to discover new breakthroughs, understand causes, and help ameliorate mental illnesses. National AMI promotes quality treatment, rehabilitation and support services, and encourages mental health professionals to be more responsive to the chronic mentally ill and their families. Its affiliates offer emotional support, case management, practical guidance, psychosocial rehabilitation, socialization, and employment services. Some affiliates maintain libraries.

*Information Services:* The national office coordinates and disseminates information and materials to affiliates. Membership applications are available from National AMI. A bimonthly newsletter is published.

**National Amputation Foundation (NAF)**  
12-45 150th Street  
Whitestone, NY 11357  
(718) 767-8400

*Handicapping Conditions Served:* Amputation.

*Users Served:* Amputees.

*The Organization:* The National Amputation Foundation (NAF) was established to help the amputee adjust to his/her handicap by encouraging integration into the general community. To this end, NAF offers: volunteer assistance to new amputees in hospitals; meetings focusing on topics of concern to amputees.

employment; and training in the use of prosthetics. NAF operates its own prosthetic center for the manufacture and repair of artificial limbs.

*Information Services:* NAF provides information on veterans' benefits and refers the amputee to possible sources of financial aid, legal assistance, and employment services. The Foundation has a reference library on amputation and materials are available for loan to any interested person. A monthly newsletter, The AMP, covers the highlights of NAF meetings.

**National Association for Hearing and Speech  
Action (NAHSA)  
10801 Rockville Pike  
Rockville, MD 20852  
(301) 897-8682 (Voice and TDD)  
(800) 638-8255 (Voice and TDD)**

*Handicapping Conditions Served:* Speech, language and hearing impairments.

*Users Served:* Disabled persons, parents, teachers, physicians, speech-language pathologists, audiologists.

*The Organization:* The National Association for Hearing and Speech Action is a membership organization of individuals with speech, hearing and language disorders, their families and interested professionals. NAHSA is primarily concerned with advocacy for the rights of the communicatively impaired and with public information activities. Its most recent effort has been a campaign of public service announcements to alert consumers about the need for early identification of communication problems and services available within their states.

*Information Services:* A Hearing and Speech HELPLINE (800-638-8255) has been set up to handle specific questions about communication problems and how to find professional assistance. The Association distributes organizational brochures and information on communication disorders. NAHSA also publishes a bimonthly newsletter NAHSA News. Some information is available in Spanish.

**National Association for Sickle Cell Disease, Inc. (NASCD)  
4221 Wilshire Boulevard  
Suite 360  
Los Angeles, CA 90010  
(213) 936-7205  
(800) 421-8453**

*Handicapping Conditions Served:* Sickle cell disease (including sickle cell anemia, hemoglobin C, and thalassemia).

*Users Served:* Disabled persons, parents, teachers, physicians, nurses, social workers, students.

...create awareness of the requirements for resolution of the problem.

NASCD provides technical assistance to its affiliates and to groups interested in setting community sickle cell programs. Affiliates conduct a variety of services, depending on particular needs of the communities they serve. Services may include: sickle cell screening, counseling to parents who possess the sickle cell trait and to patients with sickle cell disease, blood banks, tutoring, vocational rehabilitation, transportation services, babysitting, etc. The national office and its affiliates provide training to genetic counselors in how to counsel persons with sickle cell trait.

*Information Services:* NASCD's information is directed to lay persons, physicians and other professionals, and sickle cell program administrators and volunteers. Lay materials include fact sheets, audio-visuals, color prints and brochures about sickle cell trait and anemia, thalassemia and hemoglobin C. A Home Study Kit for Families includes printed materials, cassettes, games and other learning devices to help parents and other family members cope with the problems of the child or the family members. Professional materials include reprints of articles for pediatricians and genetic counselors, and a variety of manuals on the establishment of sickle cell programs, laboratory procedures for detection of the disease, and guidelines for legislation. NASCD's scientific advisory board contributes news on the latest research developments in sickle cell disease to the organization's newsletter, Sickle Cell News, published quarterly. Materials are available to all persons for a nominal fee and/or free of charge.

**National Association for Visually Handicapped (NAVH)**  
305 East 24th Street  
17-C  
New York, NY 10010  
(212) 889-3141

*Handicapping Conditions Served:* Partial vision.

*Users Served:* Disabled persons, parents, teachers, professionals, businesses.

*The Organization:* The National Association for Visually Handicapped (NAVH) provides information, referral and direct services. The latter include: (1) printing and distributing large print textbooks, educational testing materials, and books for pleasure reading; (2) offering a free loan library of large print books; (3) displaying a variety of visual aids, some available through NAVH and some through commercial sources; (4) serving as advocate for partially seeing individuals to Federal, state, and local government agencies; (5) offering youth group programs and adult discussion programs in San Francisco, and adult discussion programs in New York; (6) offering counsel and guidance to adults with partial vision and their families, to families of children with partial vision, and to all professional and paraprofessionals who work with partially seeing persons.

*Information Services:* NAVH acts as a clearinghouse of information for all services available to partially seeing persons from Federal, state, and local government agencies and from private sources. NAVH publishes materials, not available elsewhere, concerning the problems encountered by partially seeing persons. The organization publishes newsletters in large print, one for children and one for adults. The organization publishes information and...

reading material and various visual aids is also disseminated. Most information is provided in large print. Most printed materials are free of charge, although a nominal contribution is requested for some items.

## **National Association of Patients on Hemodialysis and Transplantation (NAPHT)**

**150 Nassau Street  
New York, NY 10038  
(212) 619-2727**

*Handicapping Conditions Served:* Kidney diseases.

*Users Served:* Kidney patients.

*The Organization:* The National Association of Patients on Hemodialysis and Transplantation is primarily a patient organization with approximately 10,000 members and 30 local chapters. Its purposes are: to inform the public and the patient about kidney disease; to stimulate public awareness of the need for kidney donors; to act as a consumer advocacy group at the Federal and local levels; and to provide a source of moral support to the kidney patient. The chapters function as mutual support groups; activities vary among them, but often include educational meetings with professional speakers, self-help meetings, hospital visitations to new kidney patients, group outings, and community awareness programs. NAPHT is working with vocational rehabilitation specialists to develop specific programs for the kidney patient.

*Information Services:* The national office supplies information about kidney diseases, treatments and patient rights issues. Publications include free pamphlets, such as Living With Renal Failure, Renal Failure and Diabetes, and a salt-potassium counter. State Renal Programs provides information about benefits available from state agencies. RENALIFE is a quarterly magazine which features exercise and diet suggestions, travel tips and reports of medical developments for the renal patient.

## **National Association of the Deaf (NAD)**

**814 Thayer Avenue  
Silver Spring, MD 20910  
(301) 587-1788 (Voice and TDD)**

*Handicapping Conditions Served:* Deafness, hearing impairment.

*Users Served:* Disabled persons, teachers, health professionals.

*The Organization:* The National Association of the Deaf (NAD) is a consumer oriented organization for professionals and lay persons. It recommends and promotes legislation on behalf of deaf people in areas of education, rehabilitation, legal rights for the provision of interpreters, and captioned television. NAD's Communication Skills Program sponsors a training program to upgrade instructional skills of teachers of sign language, develop instructional materials, and conduct a professional development program for teachers of deaf students.

by the Conference of Educational Administrators Serving the Deaf under contract with Department of Education. NAD has 50 state affiliates.

*Information Services:* NAD has information on where to find programs and services for deaf, including: schools, camps, interpreters, homes for the aged deaf, devices to assist deaf persons, hearing-ear dogs, and individual professional providers from medical specialists speech therapists. NAD compiled statistical information about the deaf in a 1974 National Census of the Deaf. Information regarding legislation and legal rights of the deaf is available.

The organization offers a series of workshops (most held at its biennial conference, but some offered at local meetings nationwide) for professionals and lay persons on such topics as legal concerns of the deaf, orientation to deafness, leadership training for deaf persons, and need for and implementation of mental health services for the deaf. A wide variety of books, audio-visual materials, and merchandise (stationery, bumper stickers, etc.) relating to deafness and sign language is available for sale from the NAD Publishing Division. NAD publishes three periodicals for general audiences: The Deaf American, a quarterly magazine highlighting the achievements of deaf individuals; The Broadcaster, a monthly newspaper covering legislative and legal issues; and The Interstate, a newsletter focusing on state issues and news. General information is available free from the organization. NAD has an extensive library of more than 15,000 books and other materials related to deafness. An interested person may have access to the NAD collection.

**National Ataxia Foundation (NAF)**  
600 Twelve Oaks Center  
15500 Wayzata Boulevard  
Wayzata, MN 55391  
(612) 473-7666

*Handicapping Conditions Served:* Hereditary ataxia and related conditions.

*Users Served:* Disabled persons, parents, health care professionals.

*The Organization:* The Foundation was established in 1957 to serve patients, identify persons at risk, educate the public and the medical community, and stimulate research. Eleven chapters throughout the country offer genetic counseling and moral support to affected families, make referrals to medical and other direct service providers, and raise funds for research grants. Semiannual free clinics are offered in Minneapolis and elsewhere in the country where diagnosis and other information services are available from professionals experienced in work with this neurological disorder.

*Information Services:* Free booklets, brochures, and fact sheets are available on hereditary ataxia, spastic paraplegia, Charcot-Marie-Tooth disease, hereditary tremor, and Friedreich's ataxia. A quarterly newsletter, Generations, contains reports on NAF activities, chapters, research, advice for patients and information on additional resources. It is free to members. Also available is a 22-minute slide/tape presentation on hereditary ataxia. Membership information and special publications for physicians may also be available.

12 West 21st Street  
7th Floor  
New York, NY 10010  
(212) 206-6770

*Handicapping Conditions Served:* Alcoholism.

*Users Served:* Disabled persons, parents, teachers, physicians, law enforcement personnel, TV and radio researchers.

*The Organization:* The National Council on Alcoholism, Inc. (NCA) is a voluntary health agency founded to combat the disease of alcoholism and to fight the stigma associated with this treatable disease. NCA's major areas of activity are prevention and education, public policy advocacy, publications, community services and public information programs. NCA conducts the National Alcoholism Forum, which brings together volunteers and professionals in the field. Each of NCA's 184 affiliates has its own volunteer Board of Directors and operates within the general policies of NCA. The National Council maintains a public policy office in Washington, DC.

*Information Services:* The Council stocks and distributes more than 200 books and pamphlets related to alcoholism, including titles of interest to clergy, courts, families, youth and women, as well as pamphlets by Alcoholics Anonymous. A number of these materials are available in Spanish editions. There is a nominal charge for most pamphlets and books.

**National Council On Stuttering (NCOS)**  
P.O. Box 8171  
Grand Rapids, MI 49508  
(616) 241-2372

*Handicapping Conditions Served:* Stuttering.

*Users Served:* Disabled persons.

*The Organization:* The National Council on Stuttering was established to help form local stuttering councils nationwide. There are ten local member councils in the United States, self-help groups which offer stutterers opportunities to share and learn in an atmosphere of understanding and fellowship.

*Information Services:* NCOS provides materials and suggestions to any group of stutterers interested in starting a local council. It refers stutterers to local self-help groups, and to local accredited therapy services. NCOS, in conjunction with the Speech Foundation of America, has produced a number of films on stuttering, self-help, and prevention of stuttering in children. These films are available on a loan or rental basis from the distributor, Seven Oaks Productions, 9145 Sligo Creek Parkway, Silver Springs, MD 20901 (301) 587-0330. NCOS publishes a quarterly journal covering local council news, information, and articles of interest on stuttering.

*Handicapping Conditions Served:* The aging population, including the aging disabled.

*Users Served:* All those who work with or are concerned about older people.

*The Organization:* The National Council on the Aging (NCOA), founded in 1950, a national nonprofit membership organization for professionals and volunteers, and involved in all matters affecting the quality of life of older persons. NCOA conducts research, undertakes demonstration programs, sets standards, and promotes the development of a continuum of opportunities and services for aging people, coordinating efforts with profit and nonprofit organizations. Its regional offices are located in New York City, San Francisco, and Los Angeles. NCOA's membership includes individuals, voluntary agencies, and associations, business organizations, and labor unions.

*Information Services:* Principally through its seven constituent units, affiliation with which is open to all NCOA members, the Council provides technical assistance, consultation, and information dissemination. All of these program units serve as resources and respond to inquiries in their area of concern. Each publishes a newsletter as a means of giving technical assistance to members. Several of the programs are described below.

National Voluntary Organizations for Independent Living for the Aging (NVOILA) is composed of more than 200 national voluntary, professional, service and for-profit organizations, works to promote self determination and independent living for older persons. NVOILA's recently published Directory of National Voluntary Organizations describes the efforts, resources and direct services of member groups. Other NVOILA publications include Continuum of Services: Long-Term Care of the Aging (1980), an annotated bibliography; and Long-Term Care for the Elderly: A Voluntary Sector Perspective (1981), a report of NVOILA's 1981 White House Conference on Aging Task Force, which defines the components of a continuum-of-services system and discusses key issues of planning and implementing a comprehensive system. While membership in NVOILA is open only to national organizations (an exception to the Council's policy regarding membership in constituent organizations), its newsletter is free to any interested person upon request.

The National Institute on Adult Daycare (NIAD) advocates daycare as a viable option in community-based services for disabled older persons. The Institute includes in the concept of adult daycare the following: day treatment, day health care, and partial hospitalization. NIAD makes available a brochure on adult daycare, and numerous NCOA publications.

The National Institute of Senior Centers (NISC) provides assistance to senior centers and to organizations and communities seeking to develop new centers or to expand existing services. NISC's publications include Senior Centers and the At-Risk Older Person (1980), which reports on the proceedings of a seminar covering needs identification, informal support networks, attitudes, and policy and funding; The Senior Center: A Partner in the Community Care System (1981), a package of technical assistance materials for senior center leaders and community planners; and a brochure on multi-purpose senior centers.

Two recently established programs meet needs in special areas: the National Center on Rural Aging, which advocates for older persons who live in rural areas, and the National Institute of Senior Housing, which is concerned with planning, developing, financing, and managing specially designed housing for independent older persons.

control for all long-term care planners and practitioners. Representing the entire spectrum of public and private agencies serving older persons, this unit encourages a coordinated approach to long-term care at home and in the community. NCOA publishes Perspective on Aging, a bimonthly magazine, which examines the most important issues, programs, and new developments in all areas of gerontology plus features, special reports, regular columns and book reviews concerned with the field of aging. Also available is Current Literature on Aging, an annotated bibliography of the most recent books, articles and periodicals in gerontology. Other bibliographies can be requested on adult daycare; leisure, recreation, culture and aging; education for older adults; volunteerism; and age, work and retirement. In all, NCOA has approximately 140 different books, training materials and specialized bibliographies on all aspects of aging.

A complete list of NCOA programs and constituent units and a catalog of publications are available upon request. In addition, the Council's library of materials on all aspects of aging is open to the public.

**National Down Syndrome Congress (NDSC)**  
**1640 W. Roosevelt Road**  
**Chicago, IL 60608**  
**(312) 226-0416 (In Illinois)**  
**(800) 446-3835 (Outside Illinois)**

*Handicapping Conditions Served:* Down syndrome.

*Users Served:* Disabled persons, parents, teachers, health care professionals.

*The Organization:* Formed in 1973 by a group of parents and professionals interested in Down syndrome, the NDSC now has more than 500 chapters of volunteers in the United States and around the world. These members share their experiences with other parents and professionals, promoting parent support and public awareness of Down syndrome. An annual convention and various publications keep the membership informed of medical, legislative and educational developments. Services provided by NDSC include: adoption facilitation, advocacy for adolescents and adults with Down syndrome (including their own annual convention), educational guidelines for pre-school and elementary school, text editing, research monitoring and extended family support. NDSC is governed by a 21 member board of directors which is representative of the U.S. geographically, as well as representative of a variety of ages and functional levels of children with Down syndrome.

*Information Services:* Parents are put in touch with a family support network. NDSC publishes membership brochures, a pamphlet for the lay person on Down syndrome in English, Spanish and Portuguese; Guidelines for Choosing the Preschool or Primary School for Your Child with Down Syndrome; and product availability fliers. A bibliography of materials relating to Down syndrome is being updated. The Congress publishes two newsletters. The Down Syndrome News, published ten times yearly and available only to members, covers pertinent issues covering all aspects of Down syndrome. The Parent Group Bulletin is published as appropriate when pertinent parent group information is collected and serves as an immediate communication link with persons touched by Down syndrome. NDSC provides resource information on all aspects of Down syndrome, including very technical areas, and makes referrals to local parent groups or professionals. The Congress charges a membership fee (includes newsletter) and there is a nominal charge for other



**Handicapping Conditions Served:** Down syndrome.

**Users Served:** Parents, teachers, physicians, nurses, and physical therapists.

**The Organization:** The National Down Syndrome Society (NDSS) was established in 1979 to promote better understanding of Down Syndrome and the potential of the individual with Down syndrome. Major goals are to promote basic and applied research in fields related to Down syndrome and to provide information and services to families, professionals and interested persons.

**Information Services:** NDSS concentrates on disseminating information to new parents of infants with Down syndrome and the professionals who deal with them. NDSS has produced a public information packet including a booklet entitled This Baby Needs You Even More and a bibliography of current reading materials and fact sheets. The booklet and fact sheets are available in Spanish. A list of parent groups and early intervention programs in each state is also available. In addition, a 25-minute video-cassette about the Down syndrome child, age 0-6, entitled "Gifts of Love," is offered on a free-loan basis. A newsletter, NDSS Update, is published twice a year. The Directory of Programs and Services for Children with Down Syndrome Ages 0-6, is free to individuals and contains listings of program services, and age groups served on a national basis. A materials fee is charged for bulk orders. A 24-hour 800 hot line is available to answer questions and provide referrals to resources.

**National Easter Seal Society**  
2023 West Ogden Avenue  
Chicago, IL 60612

(312) 243-8400

(312) 243-8880 (TDD)

(800) 221-6827 (Calls Outside Illinois)

**Handicapping Conditions Served:** All disabilities.

**Users Served:** Disabled persons, parents, teachers, allied health personnel, general public.

**The Organization:** The Society is the nation's largest and oldest (1919) voluntary health agency providing direct rehabilitation services to persons with disabilities. Over 800 member groups, organized on a state and local basis, provide programs which include comprehensive medical or vocational rehabilitation facilities, recreation, housing, transportation, equipment loans, public education, advocacy and other services for the prevention and treatment of disabling conditions.

The National Society, acting as headquarters for the federation of local and state organizations, conducts national public awareness and fund-raising campaigns, disseminates information and sponsors research projects for the treatment and management of disabilities.

which has been published for the past 20 years, contains original articles, book reviews, and abstracts of current professional literature. The Society has compiled bibliographies from the entries in the journal in subject areas of interest to rehabilitation personnel, persons with disabilities and their families, and Easter Seal staff and volunteers. The Society also publishes the National Easter Seal Communicator for Easter Seal volunteers (3 times per year) and Computer-Disability News for people with disabilities, computer industry officials, and rehabilitation professionals (quarterly).

The National Easter Seal Society publishes a variety of books, pamphlets and reprints for professionals, parents and persons with disabilities. Its catalog lists publications related to (1) awareness, (2) attitudes, (3) computers and rehabilitation, (4) dental care, (5) disabling conditions, (6) independent living, (7) prevention, (8) psychological aspects of disability, (9) recreation and camping, (10) rehabilitation administration and (11) volunteers. Some material is available in Spanish. For additional information about publications, contact the Publications Department. There is a nominal charge for publications or a small fee for postage and handling only.

The Society provides a full range of automation services for Easter Seal affiliates, and to agencies serving persons with disabilities, through Easter Seal Systems. Available custom software systems include Medical Rehabilitation, Vocational, Early Childhood, and Camping and Recreation, Fund Accounting, Clinic Billing, and Fund-Raising.

**National Federation of the Blind (NFB)**  
**1800 Johnson Street**  
**Baltimore, MD 21230**  
**(301) 659-9314**

*Handicapping Conditions Served:* Blindness.

*Users Served:* Disabled persons, parents, teachers, professionals.

*The Organization:* The National Federation of the Blind (NFB) is a membership organization with 51 state and 400 local chapters. NFB keeps up with Federal and state legislation affecting the blind and state services for the blind. It acts as a legislative resource for its chapters and represents the needs of blind people through advocacy and representation in discrimination cases. It attempts to arouse public awareness of the potential and accomplishments of the blind through public service messages. State and local chapters are active in developing local projects to improve conditions for the blind in areas such as mass transit, employment, and library services. Members contact newly blinded persons to help them with problems of adjustment.

*Information Services:* NFB conducts seminars on services available to the blind and what the law provides for in each state. Its National Blindness Information Center will attempt to answer any questions about blindness and the rights of the blind by phone or mail. More than 50 publications are available from NFB; some are free. NFB publishes a monthly magazine, The Braille Monitor (available in print, disc, and braille), which reports on problems, progress, activities, and new technologies related to blindness. State and local chapters refer inquirers to appropriate direct service providers.

Suite 311  
Mascoutah, IL 62258  
(618) 566-2020

*Handicapping Conditions Served:* Persons affected by any of the ectodermal dysplasia syndromes.

*Users Served:* Parents, professionals.

*The Organization:* Ectodermal dysplasias are genetic birth defects, the best known of which is Christ-Siemens-Touraine's syndrome or hypohydrotic ectodermal dysplasia. All of these conditions involve at least two abnormalities of derivatives of the skin. Symptoms may include lack of sweat glands, skin oils, hair, tears, and mucous membranes. There are often severe dental problems. There is no known test to determine the genetic carriers of these conditions. The foundation was formed to locate families encountering difficulties with an ED patient and to provide them with whatever support and information may be required. Educational materials and programs are provided to the medical community, and consultant services are available. Research programs for carrier identification and syndrome identification are currently being conducted in conjunction with major research facilities. Annual family conferences provide information, support, and social interaction. A treatment fund has been organized to provide financial assistance.

*Information Services:* The Foundation presently responds to all inquiries from families of persons with ED or their dentists or doctors. A variety of publications is available from the foundation including a monthly newsletter, A Family Guide to Ectodermal Dysplasias and Charley: The Story of a Child, a family's diary of experience with their son who has ED. Most publications are free or available for a nominal charge. Audio-visual aids are also available on a short-term loan with returnable deposit.

**National Fraternal Society of the Deaf (NFSD)**  
1300 W. Northwest Highway  
Mt. Prospect, IL 60056  
(312) 392-9282 (Voice)  
(312) 392-1409 (TDD)

*Handicapping Conditions Served:* Deafness and hearing impairments.

*Users Served:* Disabled persons, parents.

*The Organization:* Organized and administered by deaf people, the organization was originally founded to provide life insurance coverage for deaf people who were denied coverage by established companies. Membership, which entails purchase of insurance, is open to all hearing-impaired persons, their relatives and others involved in the field of deafness--between the ages of 0 and 60. NFSD advocates the rights of deaf people to drive and obtain auto insurance and works to eliminate discrimination in employment, education, and legal proceedings. The organization also awards scholastic and athletic achievement, and sponsors local and national social activities.

*Information Services:* A field force of trained representatives for information and explanation.

education is also conducted through chapters in 36 states and Canada and 106 local divisions and through the bimonthly magazine, The Frat, which carries news of the Society's insurance, social, and advocacy activities. The national office maintains an extensive library collection of monographs and pamphlets relating to deafness, which is available to any person or group for reference or research.

**National Genetics Foundation, Inc. (NGF)**  
**555 West 57th Street**  
**New York, NY 10019**  
**(212) 586-5900**

*Handicapping Conditions Served:* All genetic disorders.

*Users Served:* Physicians and the public.

*The Organization:* The National Genetics Foundation (NGF) is a nonprofit health agency dedicated to reducing the burden of genetic disease among Americans. NGF was cited by the National Academy of Sciences in 1975 as a model for health delivery.

*Information Services:* NGF's primary objective is the advancement of medical genetics into health delivery systems of the U.S. As a service to the public, the National Genetics Foundation provides a computerized analysis of an individual's personal family health history through a Family Health Profile questionnaire. The purpose is to pinpoint health problems important to the person completing the questionnaire as well as his/her children. The report of the analysis is sent to the individual's physician whose name and address must be listed on the form. There is a charge for each form and analysis to help defray the cost of service, handling and mailing.

The Foundation operates a nationwide network clearinghouse staffed by genetic counselors who provide referral to university-based genetic centers for individuals and families who have, or suspect they may have, an inherited disorder. Phone: (212) 586-5800.

**National Head Injury Foundation**  
**P.O. Box 567**  
**Framingham, MA 01701**  
**(617) 879-7473**

*Handicapping Conditions Served:* Traumatic head injuries.

*Users Served:* Disabled persons, parents, teachers, physicians, psychologists, social workers, rehabilitation counselors, nurses, therapists.

*The Organization:* Founded in 1980 by families of head-injured people and professional with an interest in the treatment of this condition, the National Head Injury Foundation assists head-injured persons and their families to seek out needed resources and services. The Foundation facilitates the formation of family emotional support groups, which exist

Directory of Head Injury Rehabilitation Services, a listing of over 350 facilities programs that meet the needs of those who have sustained head injuries. There is a nominal charge for written materials and audio-visuals. One publication, What is a Head Injury? available in Spanish.

**The National Hemophilia Foundation (NHF)**  
The Soho Building  
110 Greene Street  
Room 406  
New York, NY 10012  
(212) 219-8180

*Handicapping Conditions Served:* Hemophilia, clotting factor deficiencies.

*Users Served:* Disabled persons and their families, health care professionals, teachers, social workers.

*The Organization:* The objective of The National Hemophilia Foundation (NHF) and its chapters is to provide programs of research, professional education and training, public education and patient and community services to foster its overall goal of providing a better quality of life for individuals with hemophilia and related bleeding disorders. Chapters provide varying direct services. Some are comprehensive care treatment centers; some are affiliated with treatment centers. Most chapters sponsor scholarships and "camperships" for youths with hemophilia.

*Information Services:* The NHF provides a wide array of educational materials. Publications include general information on hemophilia for patients and their families, such as sources of possible financial assistance and medical care, educational information for employers and schools, and a variety of technical literature on care and treatment. Some professional materials are devoted to specialty areas such as dentistry, orthopedics, surgery and physical therapy. NHF also provides newsletters, study reports, conference proceedings, bibliographies, and service directories, e.g., the Directory of Hemophilia Treatment Centers. The NHF has compiled a cumulative list of health educational materials related to hemophilia, published by pharmaceutical companies, blood banking organizations, and government agencies. The pamphlet, Your Child and Hemophilia, is available in Spanish. Order forms for all publications can be requested through local chapters.

NHF chapters refer persons with hemophilia and their families to appropriate direct care facilities and to possible sources of financial assistance.

1162 Broadway  
Suite 402  
New York, NY 10001  
(212) 684-2781

*Handicapping Conditions Served:* Huntington's disease (HD).

*Users Served:* Disabled persons, parents, physicians, physical therapists, social workers.

*The Organization:* Organized in 1976 by families, professionals, and citizens concerned with HD, the Association now has 17 chapters and branches and 34 area representatives. The Association offers postdoctoral fellowships in HD and related disorders. NHDA offers patients and families support services and referrals to local facilities and resources for assistance. Public awareness is another important activity of the Association, which works to remove the stigma that has for centuries surrounded victims. HD patients often exhibit symptoms of chorea (dance-like muscular spasms) and pronounced personality change. The Association also supports medical research by fund raising and collection of autopsy brain tissue for scientists who are working on HD.

*Information Services:* Brochures explaining the inheritance and effects of the disease, a manual for medical professionals, a manual for social workers and psychologists who wish to lead support groups for HD family members, a booklet on clinical care (for physicians), reprints of articles about HD and the Association, and a list of local chapters and representatives are available on request, along with membership information and a quarterly newsletter. Referrals can also be made to local medical and nursing home facilities.

**National Kidney Foundation (NKF)**  
Two Park Avenue  
New York, NY 10016  
(212) 889-2210

*Handicapping Conditions Served:* Genitourinary disorders, chronic renal malfunction.

*Users Served:* Disabled persons, physicians, nurses, technicians, dieticians.

*The Organization:* Since 1950, the National Kidney Foundation (NKF) has been seeking the total answer to diseases of the kidney and urinary tract - prevention, treatment and cure-through research, patient services, nationwide organ donor programs, professional education and public information. The Organ Donor Program works through 50 affiliates to gather kidneys and other organs for transplant. Support of blood banks for dialysis patients, administration of detection and screening programs, and staffing of information and referral offices along with advocacy and public information activities are among the activities of Foundation affiliates and 200 local chapters. NKF sponsors symposia, conferences and meetings for medical and allied health professionals. Education of professionals is provided by five Councils of the Foundation: Clinical Nephrology, Dialysis and Transplantation, Nephrology Social Workers, Renal Nutrition, Urology and Nephrology Nurses and Technicians.

**Information Services:** Affiliates and local chapters provide counseling and referrals to local resources for patients and their families. The Foundation provides a number of brochures for patients and families covering general information on kidney and urinary tract disorders, specific diseases, treatment options, diet and rehabilitation. Sample titles are: What Everyone Should Know About Kidneys, Your Kidneys and How to Detect Kidney Disease, and High Blood Pressure and Your Kidneys. Some information is available in Spanish. Publications include a bimonthly newsletter containing up-to-date information on research, legislation, programs and services and learning opportunities; The Kidney, a bimonthly scientific report on single topics of current research and clinical developments in kidney disease; and The American Journal of Kidney Diseases, a monthly journal focusing on human renal and urogenital function in health and disease primarily for physicians and researchers. Audio-visuals are available on the physiology of the kidney, chronic renal failure, treatment and organ donation. Materials are free to patients; a nominal fee is charged for health care professionals.

The National Marfan Foundation (NMF)  
54 Irma Avenue  
Port Washington, NY 11050  
(516) 883-8712

**Handicapping Conditions Served:** Marfan syndrome.

**Users Served:** Disabled persons and their families, health care professionals.

**The Organization:** The National Marfan Foundation is an organization founded in 1982 to meet the needs and interests of individuals with the Marfan syndrome. This syndrome is a genetic disorder of the connective tissue that affects many organ systems, including the skeleton, the lungs, the eyes and the heart and blood vessels. While difficult to diagnose, it is estimated that over 20,000 people in the U.S. have the Marfan syndrome.

The National Marfan Foundation has a threefold purpose: (1) to provide accurate and timely information about this condition to patients, family members and physicians; (2) to provide a means for patients and relatives to share experiences, to support one another, and to improve their medical care; and (3) to support and foster research. The NMF is working to provide grants to research scientists in support of their investigations into the causes and treatment of the Marfan syndrome. Fund raising for research and patient service is a major activity. The Foundation is composed of over 10 chapters and community groups across the country.

NMF publishes a variety of materials for patients, the public and copies of printed materials are available free from the national office; Bulk orders. Publications include The Marfan Syndrome, which description of the condition, and How John Was Unique, a picture-on with the condition. Fact sheets on the syndrome and NMF are hly newsletter, Connective Issues, is free to members. Audio-visuals meeting and a TV interview show featuring two persons affected by are offered for loan or purchase. Additional materials are available

**Alexandria, VA 22314-2971**  
**(703) 684-7722**

*Handicapping Conditions Served:* Mental and emotional disorders.

*Users Served:* Disabled persons and their families, professionals.

*The Organization:* Formerly the National Association for Mental Health, the NMHA adopted its present name in 1976. Primarily an advocacy and public education organization, NMHA and its 650 local chapters work for legislation affecting the rights and treatment of the mentally ill. On occasion it will engage in litigation, where a test case seems warranted, on such issues as regulation of electroconvulsive therapy, patients' rights to refuse drugs, or rights to counsel during commitment hearings. NMHA works for improved community-based treatment facilities to replace outmoded state hospitals, and it carries on public awareness campaigns to effect changes in neighborhood and business community attitudes toward recovered mental patients.

*Information Services:* An extensive publications list includes such titles for patient and family as Helping the Mental Patient at Home, and What Every Child Needs for Good Mental Health. Of interest to the general public are such publications as How to Deal With Your Tensions, Depression: What You Should Know About It, and When Things Go Wrong, What Can You Do? Information on services, insurance, research, employment, legislation and litigation, careers in mental health, rehabilitation, and citizen activism is also available, as well as NMHA position statements on topics ranging from psychosurgery to the insanity defense. A monthly newsletter, Focus, informs members of news in the mental health field. Films and other educational materials are available for one-day rentals; a catalog will be sent on request. Inquiries and referrals for direct service are handled by local affiliates.

**National Multiple Sclerosis Society**  
**205 East 42nd Street**  
**New York, NY 10017**  
**(212) 986-3240**

*Handicapping Conditions Served:* Multiple Sclerosis and related diseases.

*Users Served:* Disabled persons and their families, health care professionals, general public.

*The Organization:* The National Sclerosis Society provides funding for research, public and professional education, advocacy and the design of rehabilitative and psychosocial programs. Direct services to MS persons are provided through 161 local chapters and branches. A Washington office is active in advocacy for federal legislation affecting MS persons and NIH research funding. Among the programs offered by chapters are a variety of counseling and referral services; many offer group aquatics and other social/recreational support activities. Sixty-seven clinical diagnostic and treatment centers are supported by local chapters in 30 states. The Society is a member of the International Federation of Multiple Sclerosis Societies.

*Information Services:* Publications for the general public include such pamphlet titles as What Everyone Should Know About Multiple Sclerosis and Living with MS: A Practical



Claims in Multiple Sclerosis are also available. Patient information includes pamphlets on mental and emotional health, careers for the homebound and Inside MS, a quarterly membership periodical. Some information is available in Spanish. Professionals may request publications on treatment, nursing care, group counseling, and reprints of journal articles. Referrals, information on technical aids and equipment, and order lists for free publications can be obtained from chapters.

**National Network of Learning Disabled Adults (NNLDA)**  
P.O. Box 716  
Bryn Mawr, PA 19010  
(215) 275-7211

*Handicapping Conditions Served:* Learning disabilities.

*Users Served:* Disabled persons.

*The Organization:* The National Network of Learning Disabled Adults (NNLDA) is an organization formed to provide support, assistance and information to learning disabled adults and self-help groups for learning disabled adults nationwide. NNLDA encourages advocacy and provides an informal communication network among members, which it plans to formalize in the future. In addition, NNLDA works to educate the public about learning disabilities and about the abilities of those who have LD. Assistance is provided to LD adults in locating appropriate services. NNLDA has three state chapters.

*Information Services:* NNLDA publishes a descriptive brochure about the organization. The NNLDA Newsletter, published four times per year, reports on educational programs and resources, legislation, government policies, employment and training opportunities, organizational news and other items of interest. LAUNCH, a member organization, offers a video tape for sale about LD adults. NNLDA provides speakers for organizations and conferences. The Network maintains an electronic bulletin board entitled LD ADULT on Special Net (see National Association of State Directors of Special Education, separate entry) to disseminate information about issues of concern to LD adults. There is no charge for information or services.

**National Neurofibromatosis Foundation (NNFF)**  
141 Fifth Avenue  
Suite 7-S  
New York, NY 10010  
(212) 460-8980

*Handicapping Conditions Served:* Neurofibromatosis (Von Recklinghausen's disease).

*Users Served:* Disabled persons, parents, health care professionals.

*The Organization:* Neurofibromatosis (NF) is an inherited neurological disorder which can affect all areas of the nervous system and the skin. Symptoms of the disorder usually begin in childhood or adolescence, when children exhibit characteristic skin lesions, freckles, and

7 state chapters, support groups for members. It recently cosponsored along with the New York Academy of Sciences an international Conference on Neurofibromatosis which brought together a distinguished group of physicians and scientists to focus on the disorder. NNFF also awards research grants and fellowships. NNFF members include affected individuals and families, physicians and other interested persons.

*Information Services:* NNFF publishes a brochure entitled Neurofibromatosis: Information for Patients and Families, a quarterly newsletter, and a research newsletter for professionals. The Foundation assists individuals affected by NF and their families in finding medical, social and genetic counseling. A patient brochure in Spanish is being prepared.

**National Organization on Disability (N.O.D.)**  
**2100 Pennsylvania Avenue, NW**  
**Suite 234**  
**Washington, DC 20037**  
**(202) 293-5960**  
**(202) 293-5968 (TDD)**

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons, parents, teachers, community-level administrators, national organizations, employers.

*The Organization:* The privately funded National Organization on Disability, successor organization to the U.S. Council for the International Year of Disabled Persons, works to support community-based efforts to improve the lives of disabled people. Emphasis is placed on the concept of partnership between able-bodied and disabled individuals in developing cooperative programs. The N.O.D. encourages organizations, corporations and others to support local efforts, and offers technical assistance to the growing number of participating communities. To date, there are 50 state chapters and approximately 1700 local chapters of N.O.D. The National Organization sponsors annual programs for Community Partners and National Partner Organizations at which it awards cash prizes for progress made at these levels toward integrating citizens with disabilities into community life.

*Information Services:* In conjunction with the National Technical Institute for the Deaf, the N.O.D. publishes Organizing Community Partnership Programs, a 30-page guide which discusses community goal-setting, dealing with the media, fund raising, working with elected officials and more. The N.O.D. also publishes a quarterly REPORT which highlights the organization's program activities and current disability trends. REPORT is available to the general public. UPDATE, a bimonthly newsletter is targeted to community partner groups and highlights replicable community projects and available resources. N.O.D. has a clearinghouse which also stores this information. Limited assistance can be provided to individual inquiries. All information is available on cassette tapes.

1401 Mt. Royal Avenue  
Fourth Floor  
Baltimore, MD 21217  
(301) 225-9400  
(301) 225-9409 (TDD)  
(800) 638-2300 (Outside Maryland)

*Handicapping Conditions Served:* Blindness and visual impairments, caused by inherited retinal degenerative diseases.

*Users Served:* Disabled persons, parents, teachers, rehabilitation workers, ophthalmologists, optometrists, geneticists, mobility specialists, psychologists.

*The Organization:* The National Retinitis Pigmentosa Foundation funds research in retinitis pigmentosa (RP) and other retinal degenerative diseases. It funds 13 research centers in the U.S. and England, each involved in different but coordinated areas of investigation into retinal degenerative diseases. The RP Foundation maintains a national confidential register of RP affected persons for statistical and clinical research. In addition the Foundation has initiated an RP Retina Donor Program to assist the researchers' efforts. The organization's 60 affiliates are involved in a variety of activities including information and referral experience sharing, and fund raising. Furthermore, the National RP Foundation is a part of the International Retinitis Pigmentosa Association, a coalition of 17 countries which coordinate research on a world wide basis.

*Information Services:* Volunteer Information Resource Centers (VIRC) plus the chapters provide referral services to rehabilitation, psychological, medical, genetic, and vocational counseling agencies. The RP Foundation publishes several fact sheets, an annual report and a quarterly newsletter for the lay reader. The newsletter is available on cassette and one brochure is available in Spanish. There is no charge for single copies of all materials. The RP Foundation holds regional and national educational workshops for volunteers and professionals, where leading speakers in the field of RP are featured.

**National Reye's Syndrome Foundation (NRSF)**  
426 North Lewis  
Bryan, OH 43506  
(419) 636-2679

*Handicapping Conditions Served:* Reye's syndrome.

*Users Served:* Physicians, general public.

*The Organization:* Formed in 1974, NRSF, a nonprofit organization, has grown to over 140 chapters in 41 states. It promotes awareness of Reye's syndrome, which strikes children from infancy to about 19 years of age, most commonly after a viral illness such as flu or chicken pox. If not diagnosed and treated in its early stages, Reye's syndrome can lead to brain damage ranging from light to severe. NRSF provides funds for basic research on the disease, and support and guidance to families of stricken children.

*Information Services:* NRSF disseminates literature to the lay community and the medical profession, such as brochures.

public. Two additional programs for in-service hospital training sessions are technical in nature and designed for members of the health profession. There is a nominal charge for large quantities of brochures. NRSF publishes the annual Journal of the National Reye's Syndrome Foundation and a biannual newsletter, In The News. The Foundation compiles statistics and data on Reye's syndrome.

**The National Society for Children and Adults with  
Autism (NSAC)**  
1234 Massachusetts Avenue, NW  
Suite 1017  
Washington, DC 20005-4599  
(202) 783-0125

*Handicapping Conditions Served:* Autism.

*Users Served:* Parents, teachers, professionals.

*The Organization:* NSAC, The National Society for Children and Adults with Autism, is an organization of parents, teachers, professionals and interested people who work for legislation, education, and research for the benefit of all children with severe disorders of communication and behavior. Advocacy on the national, state, and local levels, particularly in the area of education, is a primary function of the organization. The 190 local chapters of NSAC support various direct services, such as recreational programs and group homes (residences for 8 to 12 children).

*Information Services:* The organization publishes general pamphlets defining autism and suggesting management techniques. NSAC's Information and Referral Service, located at the above address, has specific information available, including: (1) names, addresses, and other information about day and residential programs and camps which admit children with autism; (2) a list of facilities which admit autistic adolescents and adults; (3) ways to effectively organize to get community services for children with autism; (4) legislative information at national and state levels; (5) suggestions for sources of funds, public and private; (6) a list of colleges and universities which offer training in the field of autism; (7) income tax information for parents; (8) a list of contacts and societies for children with autism in other countries. The service also keeps an informal list of research projects being conducted in the area of autism.

NSAC publishes a bimonthly newsletter, The Advocate, an advocacy publication geared toward parents and professionals who work with autistic children. NSAC also publishes the annual Proceedings of Society National Conferences, which includes professional papers on a variety of subjects related to autism. Books about autism for the professional and lay reader are selected and distributed by NSAC's bookstore. These include NSAC publications such as How They Grow: A Handbook for Parents of Young Children with Autism and Critical Issues in Educating Autistic Children and Youth, produced in cooperation with the Office of Special Education Programs, U.S. Department of Education.

*Users Served:* Parents, teachers, doctors, nurses, and safety professionals.

*The Organization:* This organization, founded in 1908, works to prevent blindness by sponsoring community screening and testing programs, public and professional education, and research. Community programs, carried on through 26 affiliated volunteer staff agencies, concentrate on health education and free screening for the public. These programs aim to detect, control, correct, or prevent glaucoma and cataract blindness; eye problems in children; eye accidents; and blindness caused by hereditary and congenital conditions, diabetes, and macular degeneration. NSPB works for the implementation of laws for eye protection in hazardous environments. It funds research in eye care and disease prevention.

*Information Services:* NSPB provides answers to specific questions about eye diseases, eye safety, vision defects, and eye checkups when queried by mail. It publishes brochures and pamphlets on various subjects, such as glaucoma, cataracts, sunglasses, and TV and the eyes, providing single copies of most materials at no charge. NSPB publishes a newsletter, three times a year and a quarterly magazine. Low-cost curriculum aids for teachers are also available. A complete catalog of NSPB publications and films may be obtained by writing to NSPB, enclosing a stamped, self-addressed, business sized envelope.

**National Spinal Cord Injury Association**  
**149 California Street**  
**Newton, MA 02158**  
**(617) 964-0521**

*Handicapping Conditions Served:* Spinal cord injuries caused by trauma and disease.

*Users Served:* Disabled persons and their families, physicians, nurses, therapists, social workers, rehabilitation counselors.

*The Organization:* Founded by the Paralyzed Veterans of America in 1948, the National Paraplegia Foundation in 1979 merged with the New England Spinal Cord Injury Foundation and adopted the present name. Dedicated to programs of research and service, the Association works through its 30 chapters to develop comprehensive systems of quality care for paraplegics and quadriplegics. Care is offered as a direct service by some chapters which give individual case consultations and advise on case management of the newly injured. Other chapters make referrals to direct service providers. All chapters emphasize personal contact between persons with spinal cord injuries and involve them in all aspects of activities. Cure is the goal of the research division which offers fellowships to neuroscientists who are working in the field of repair or regeneration of the spinal cord. Regional seminars and an annual conference give professionals, constituents, and other interested persons an opportunity to exchange and compare new developments in technological, environmental, and medical research. Coping with the disability is facilitated by peer counseling; public awareness; and environmental barrier removal. Some chapters sponsor independent living rehabilitation programs and more of these are being developed for the severely disabled (quadriplegic).

medical and other health care workers. Information on independent living rehabilitation programs, self-help devices, equipment, transportation, employment, education, personal care, and referrals is available from the national office and through chapters. Individual case consultations and case management advice can also be requested; contacts can be arranged for person-to-person assistance and peer counseling, if appropriate. Publications include Spinal Cord Injury Life, a bimonthly newsletter; regional and national resource directories; and handbooks on nursing, personal care, and nutrition. Interested persons may also request bibliographies of current and relevant research. In general, there is no charge for services or publications to persons with spinal cord injuries; there is a minimal charge to others for some publications.

**National Stroke Association (NSA)**  
**1420 Ogden Street**  
**Denver, CO 80218**  
**(303) 839-1992**

*Handicapping Conditions Served:* Disabilities related to stroke.

*Users Served:* Stroke survivors and their families, physicians, nurses, physical, occupational and speech therapists, other rehabilitation professionals, rehabilitation centers and community stroke organizations.

*The Organization:* NSA is the only national organization focusing its efforts solely on cerebral vascular accidents (CVAs or strokes). Its goal is the reduction of stroke incidence and the provision of a strong, visible, nation-wide education, information and referral service for stroke survivors, their families, health professionals and the lay community. NSA also maintains a research program focused on the prevention, treatment and rehabilitation of stroke. The program is guided by the NSA Scientific Advisory Committee, which is composed of nationally recognized, stroke-knowledgeable medical professionals. The NSA was founded in 1984 and its first state chapter office will open in 1986.

*Information Services:* This Association publishes a quarterly newsletter, Open Channels, as a tool for exchanging stroke-related experiences and other information. All NSA members receive this publication, which contains articles from practitioners, researchers, stroke survivors and their families. The NSA also publishes a series of educational materials entitled Be Stroke Smart. A stroke recovery guide, The Road Back, is available as of December, 1985.

The NSA's clearinghouse is collecting a broad range of stroke information and data on available services. The clearinghouse is developing a Stroke Resource Catalog and is collecting audio-visual materials for loan to interested groups. In addition, inquirers are referred to local services and support groups when appropriate.

*Users Served:* Disabled persons, parents, teachers, speech therapists.

*The Organization:* Established in 1977, the NSP is a self-help organization run by and for people who stutter, serving over 2,000 members nationwide. NSP provides information on all aspects of stuttering to people who stutter and the general public. In 35 self-help groups, NSP runs biweekly meetings where people who stutter can come, share, learn about themselves, and have fun speaking in a specially designed meeting format. NSP offers consultations in program development and technical assistance to school districts, speech clinics, hospitals, rehabilitation centers, and other agencies involved in speech services.

*Information Services:* The NSP publishes a monthly newsletter called Letting Go which is available only to members. Publications also include pamphlets and article reprints with such titles as: "What Teachers Can Do to Help the Child Who Stutters" and "A Personal Journey Through Stuttering." A tape series, which includes a tape of a chapter meeting, and the handbook, Self Therapy for Stuttering, are available at nominal cost. NSP has a Speech Pathology Referral Service which provides information on experienced speech therapists. Speakers and slide show presentations may be requested by schools and other organizations.

**National Tay-Sachs and Allied Diseases Association,  
Inc. (NTSAD)  
92 Washington Avenue  
Cedarhurst, NY 11516  
(516) 569-4300**

*Handicapping Conditions Served:* Tay-Sachs and other inborn errors of metabolism.

*Users Served:* Parents, physicians.

*The Organization:* National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD) is an organization that supports research, provides educational literature on Tay-Sachs and other allied disorders, acts as a referral agency for families with afflicted children and encourages screening. Tay-Sachs is an inherited disorder caused by the absence of a vital enzyme, which results in destruction of the nervous system and fatality, usually by age five. NTSAD provides information about screening for possible carriers of the Tay-Sachs gene and can direct interested persons to screening centers and genetic counseling services nationwide. NTSAD supports the Quality Control Program to accredit laboratories doing analysis of samples. To facilitate interaction between parents of children with these disorders, NTSAD has formed a Parent Peer Group Network to provide emotional support and offer practical guidance on a personal level.

*Information Services:* Brochures for lay and professional persons describe the disease and recommend preventive measures through carrier testing and genetic counseling. A list of Tay-Sachs screening centers in the U.S., Canada and other foreign countries is available to medical professionals. NTSAD publishes a semiannual newsletter, Breakthrough, to report

on legislation, research developments, Association activities and chapter news. One pamphlet is available in Russian and some information is offered in French. There is no charge for services or publications.

**National Tuberous Sclerosis Association, Inc. (NTSA)**  
**National Headquarters**  
**P.O. Box 612**  
**Winfield, IL 60190**  
**(312) 668-0787**

*Handicapping Conditions Served:* Tuberous Sclerosis (TS).

*Users Served:* Parents, neurologists, pediatricians, dermatologists and other medical specialists.

*The Organization:* The Association was founded in 1975 by parents and concerned physicians of patients with this genetic disorder which results in tumors in any organ including the brain, convulsions, skin lesions, and, in severe cases, mental retardation. Research, accurate diagnosis, anti-convulsant therapy, and early developmental intervention are the goals of the organization. Dissemination of information to the medical profession as well as to parents and the general public, advancement of research by fund raising, and annual meetings for researchers and for the Association's membership of parents and professionals implement these goals. The Association has established a national Human Neurospecimen Bank and a case registry to assist scientists in their research. The members of the Association offer counseling, referral, and support services to other families of TS patients.

*Information Services:* A parent booklet, an illustrated medical brochure and a clinical brochure listing the location of NTSA state representatives are all free upon request. A 20-minute slide presentation is available for loan. A 30-second public service tape can be supplied to any local media. NTSA attends all major medical conventions. NTSA's quarterly newsletter provides up-to-date information on treatment and research. An annual membership fee includes all mailings and a free newsletter subscription.

**Orton Dyslexia Society (ODS)**  
**724 York Road**  
**Baltimore, MD 21204**  
**(301) 296-0232**

*Handicapping Conditions Served:* Dyslexia.

*Users Served:* Disabled persons, parents, teachers, health care professionals.

*The Organization:* The Orton Dyslexia Society (ODS) is an international membership



*Information Services:* ODS can provide some general information to inquirers by phone or by letter; most information requests are met through a variety of ODS publications on dyslexia and related learning disabilities. There is a charge for books and a nominal fee for most pamphlets and article reprints. The ODS Annals of Dyslexia (formerly the ODS Bulletin) is a compilation of scientific papers delivered at its annual conference, containing therapy applications and articles about the state of the art. Audiotapes of individual conference papers are available. ODS also publishes a quarterly newsletter, Perspectives on Dyslexia, containing pertinent local and national information.

## **Osteogenesis Imperfecta Foundation, Inc. (OIF)**

**P.O. Box 838**

**Manchester, NH 03105**

**(603) 623-0934 (Editorial Office)**

**(516) 325-8992 (Administrative Office)**

*Handicapping Conditions Served:* Osteogenesis imperfecta (brittle bone disease).

*Users Served:* Disabled persons, parents, teachers, health care professionals.

*The Organization:* The Foundation was organized in 1970 by parents of children suffering from this genetic defect. Characterized by fragility of bone and often by stunted growth, the condition displays a wide range of severity. Management of the disease and treatment of symptoms, which may include hearing and dental problems as well as frequent fractures is now available at many hospitals and medical centers. Referral to genetic counselors is another service offered to affected families. Public awareness and fund raising to support research are other activities of the organization. Members are adult patients as well as parents of children with the disease.

*Information Services:* Information about medical facilities and services, care and management techniques, and equipment is available from the Foundation office or any of the 12 local chapters. Pamphlets describing the disease and its management; a guide to education for children with osteogenesis imperfecta; reprints of articles by parents, researchers, and health care professionals; a quarterly newsletter, Breakthrough; and referrals to local chapters and medical facilities are available from the Foundation.

## **Paralyzed Veterans of America (PVA)**

**801 Eighteenth Street, NW**

**Washington, DC 20006**

**(202) 872-1300**

*Handicapping Conditions Served:* Paralysis caused by spinal cord injury or disease.

*Users Served:* Paralyzed veterans, families, health care professionals, and the broad univers of disabled persons.

*The Organization:* Paralyzed Veterans of America (PVA) is a national organization for paralyzed veterans with offices in each of the Veterans Administration's (VA) 20 Spinal Cord Injury Centers and many VA regional offices and outpatient clinics. PVA operates a

educational opportunities. PVA representatives plead claims for paralyzed veterans before the Veterans Administration. The organization has more than 40 state chapters and 22 sub-chapters which help the PVA carry out its programs. One of PVA's chapter-oriented programs trains nurses in the care and treatment of spinal cord injury patients. PVA sponsors and supports wheelchair sports and recreation.

*Information Services:* PVA publishes brochures and other materials on such subjects as architectural barriers, research related to spinal cord injury, veterans benefits, disability-related legislation, and sports. It provides statistical data (e.g., VA health care utilization) and technical assistance materials on architectural barrier removal and adaptive devices. PVA also publishes two magazines, Paraplegia News, and Sports and Spokes.

**Parent Care  
University of Utah Medical Center  
Suite 2A210  
Salt Lake City, UT 84132  
(801) 581-5323**

*Handicapping Conditions Served:* Handicaps resulting from premature birth.

*Users Served:* Perinatal professionals, psychologists, hospital administrators, occupational therapists, behavioral scientists, developmental specialists, social workers, parents, and concerned citizens.

*The Organization:* Parent Care, formerly Parents of Premature and High-Risk Infants, Inc. (PPHRI), was established in 1982 by a group of parents and professionals to provide a national focal point for information, referral, and support for families of infants who require special care at birth. The goals of the organization are to support families with critically ill newborns, to encourage communication between parents and perinatal professionals, to initiate and support parent support groups, to facilitate networking between parent support groups and health care agencies, and to enhance public awareness of the special needs of families of premature and high-risk infants.

*Information Services:* Parent Care publishes a quarterly newsletter, Parent Care Newsbrief, which is free to members. It also publishes a Resource Directory which lists support groups throughout the country, and reviews books and other materials in this field. There is a small charge for most materials (members receive reduced rates).

For information regarding membership, educational materials, and proceedings from the 1984 and 1985 Parent Care conferences, contact the national headquarters at the above address.

**Pediatric Projects, Inc. (PPI)  
P.O. Box 1880  
Santa Monica, CA 90406**

corporation which serves as an educational and advocacy group, promoting the mental health of children in health care. PPI develops and distributes medically-oriented therapeutic toys and books for children and publications for parents and professionals about helping children to cope with illness, disability, treatment and hospitalization. In addition to materials, the organization provides educational sessions and consultations to encourage quality mental health approaches to the physical care of ill or disabled children.

*Information Services:* Besides brochures about the organization, PPI provides information about preparing children psychologically for treatment and hospitalization, developing therapeutic play programs in medical settings and assisting children and their families in coping with illness. Pediatric Mental Health is a bimonthly newsletter, available by subscription. It includes articles on parenting, play and preparation for treatment and hospitalization, with interviews and reports of research, written in readable style. Issues in Pediatric Mental Health is a monograph series, covering gaps in practice and research and providing extensive bibliographies. PPI also publishes books for children, parents and professionals on coping with treatment and hospitalization and extensive series of bibliographies on specific illnesses, disabilities and treatments. Curriculum materials in the form of both fiction and non-fiction books help children understand the disabilities of their friends, neighbors and classmates. Some publications are available in Spanish.

Also available from PPI are two videocassette series. "Growing Up With Cancer" is a two-part series about school re-entry after cancer treatment. A "Mr. Rogers" series for young children discusses going to the hospital, having an operation and having a cast.

All publications, videos and medically-oriented toys are available by mail order for reasonable charges. Catalog requests should be sent to PPI.

Pediatric Projects, Inc. provides technical assistance to medical and nursing staffs in developing new programs and improving existing ones so that attention is given to the mental health and development of children in clinics and hospitals. Consultation, seminars and workshops are available for a fee.

**People First International**  
**P.O. Box 12642**  
**Salem, OR 97309**  
**(503) 378-5143**

*Handicapping Conditions Served:* Mental retardation and developmental disabilities.

*Users Served:* Disabled persons, parents, teachers, any persons interested in self-advocacy.

*The Organizations:* People First International is an organization of mentally retarded and developmentally disabled individuals who meet to learn leadership skills and self-advocacy techniques. People First began in Salem, OR in 1973. Since then, more than 50 local chapters have been established across the U.S. and Canada. The national office provides assistance through consultation and information to groups seeking to establish chapters. People First is currently working towards establishing a People First/U.S.A. Network.

*Information Services:* Information about People First and setting up programs is available from the organization. Materials include a "how-to" booklet, an officer's booklet and several

about workshops, a People First film and a book telling the story of "We Are People First" can be obtained from the national office, as well as the location of local chapters. Some local groups publish newsletters about their activities; one Canadian group prints a newsletter in French.

**The Phoenix Society**  
**11 Rust Hill Road**  
**Levittown, PA 19056**  
**(215) 946-4788**

*Handicapping Conditions Served:* Burn victims.

*Users Served:* Burn victims and their families.

*The Organization:* A self-help organization established in 1977 for burn victims and their families, the Phoenix Society works to ease the psychosocial adjustment of severely burned persons during and after hospitalization so that they can return to normal lives within their communities. While anyone with an interest in the goals of the Society is free to join, members are in large part recovered burn victims, who volunteer to help patients and their families on a one-to-one basis. Members work under the supervision of attending hospital staff.

*Information Services:* Burn victims and their families who would like to get in touch with other burn victims for counseling or help may contact the Phoenix Society for referral to the nearest regional coordinator. If there is no coordinator close enough, the Society will make arrangements for a volunteer to contact the inquirer.

The Society publishes a quarterly newsletter, The Icarus File, which is included with membership. Nonmembers may subscribe for a nominal charge. In addition, a list of audio-visual materials on fire prevention, burn care, true life stories of burn victims, and other topics is available from the Society. Information and/or assistance is available in Spanish; the Society is prepared to make arrangements for other languages as necessary.

**Prader-Willi Syndrome Association**  
**5515 Malibu Drive**  
**Edina, MN 55436**  
**(612) 933-0113**

*Handicapping Conditions Served:* Prader-Willi syndrome.

*Users Served:* Parents, teachers, health care professionals.

*The Organization:* Prader-Willi syndrome is a rare condition which results from a birth defect. Those with this sporadically occurring disorder suffer obesity, if untreated, short

capacity of the Prader-Willi child as well as tips on management, diet and exercise. Prader-Willi Syndrome, an overview by Suzanne Cassidy, M.D., may also be purchased. There is a nominal charge for materials. An overview of the syndrome is available in French and Spanish. The Association provides information to parents regarding physicians or hospitals with specific knowledge of the syndrome.

**Recovery, Inc.**  
**The Association of Nervous and Former Mental Patients**  
**802 North Dearborn Street**  
**Chicago, IL 60610**  
**(312) 337-5661**

*Handicapping Conditions Served:* Emotional disorders and mental illness (after-care).

*Users Served:* Disabled persons.

*The Organization:* Founded in 1937 to provide self-help after care for released patients, psychiatrist Abraham Low, the organization uses Low's techniques of describing and coping with daily problems to prevent relapse or chronicity. All leadership is voluntary and group members follow procedures established by Dr. Low. Health care professionals are welcome as consultants or observers, but weekly meetings are conducted by members who are lay leaders and former patients. It is not necessary to have been under the treatment of a physician or to have been hospitalized to join Recovery; many members come through personal referral, newspaper publicity as well as professional referral. There are 1,000 chapters in the U.S., Canada, Ireland, the United Kingdom, and Puerto Rico.

*Information Services:* The techniques on which the organization is based are presented in the handbook by Dr. Low, Mental Health Through Will Training (available also in Spanish and French). Other Low lectures are available on cassettes or records; topics range from "The Fear of Life Ebbing Away" to "The Obsession of Being Contaminated." Pamphlets, the organization, a bimonthly newsletter, reprints of articles describing the organization, a publications list, and a directory of group meetings can be requested. The organization prefers to offer demonstration meetings instead of speakers at gatherings of professional organizations or other interested organizations. Contact the headquarters office for information on services.

**Self Help for Hard of Hearing People (SHHH)**  
**7800 Wisconsin Avenue**  
**Bethesda, MD 20814**  
**(301) 657-2248 (Voice)**  
**(301) 657-2249 (TDD)**

*Handicapping Conditions Served:* Hearing impairment.

*Users Served:* Disabled persons, parents, teachers, audiologists, otolaryngologists, and rehabilitation agencies.

International educational organization of hard of hearing persons and others concerned with this disabling condition. SHHH seeks to educate hearing-impaired persons about hearing loss detection, management, and prevention of further loss, and to develop public and professional acceptance of the needs of hard of hearing people. Over 100 chapters have been formed in 33 states. The SHHH Research Center is being established to promote research into the treatment and prevention of hearing loss. This Center will function as the grant-making arm of SHHH.

*Information Services:* SHHH publishes a bimonthly journal about hearing loss and relevant aids, communication techniques and programs, and a newsletter for chapter organizers. The organization also offers information and referral services. Publications are available on a variety of topics including hearing aids, assistive listening devices, communications access systems for groups and large rooms, the psychological effects of hearing loss and assertiveness training for hard of hearing people. There is a charge for most publications.

**Sensory Aids Foundation (SAF)**  
399 Sherman Avenue  
Suite 12  
Palo Alto, CA 94306  
(415) 329-0430

*Handicapping Conditions Served:* Blindness and visual impairment, deafness/hearing disorders.

*Users Served:* Disabled persons, employers, rehabilitation counselors.

*The Organization:* The Sensory Aids Foundation (SAF) is a nonprofit organization in operation since 1972, which introduces employers to the kinds of services and equipment they need in order to employ handicapped persons. Major services provided are: (1) employer orientation to sensory aids equipment and assistive devices used in making jobs accessible for handicapped people; (2) identification of specific jobs which handicapped persons may perform competitively; (3) identification of equipment used by handicapped persons; (4) identification of new areas of employment for handicapped persons; (5) maintenance of C-TEC (Computer Training and Evaluation Center) for hands-on training on computer access equipment; and (6) Vidvox - a research and development program on communication aids for deaf persons.

*Information Services:* Services are provided to potential employers, rehabilitation counselors, and handicapped persons. SAF publishes the SAF Quarterly journal, Technology Update (a monthly subscription newsletter) and Sensus, a quarterly magazine. Both Sensus and Technology Update are concerned with new equipment, new applications and new techniques to assist visually and hearing-impaired persons.

**Sick Kids (Need) Involved People, Inc. (SKIP)**  
216 Newport Drive  
Severna Park, MD 21146  
(301) 647-0164

ultimate goal. SKIP has approximately 25 chapters nationwide and is expanding in all of the country. Chapters provide information, education and support over the telephone and through group meetings. Professionals such as physicians, social workers, psychologists and counselors participate in group meetings through educational presentations and facilitators to encourage parental interaction. Parent networking to offer peer support mutual aid is an important component of SKIP services.

*Information Services:* SKIP puts out printed materials and sponsors educational presentations dealing with home care of technology-dependent children. The organization also publishes a newsletter. Donations for individual membership are requested, but are required.

**Society for the Rehabilitation of the Facially Disfigured**  
550 First Avenue  
New York, NY 10016  
(212) 340-5400

*Handicapping Conditions Served:* Facial disfigurement and deformities of the hands and extremities.

*Users Served:* Disabled persons, parents, physicians.

*The Organization:* The Society was founded to provide programs of public education and research, to establish new treatment facilities, and to encourage training in reconstructive plastic surgery as a means of aiding victims of facial disfigurement. The Society's Institute of Reconstructive Plastic Surgery at the New York University Medical Center functions as a center for clinical services, professional training, and medical research, in association with several plastic surgery clinics in the New York metropolitan area. Research emphasizes three major areas: facial and hand reconstruction, microsurgery, and replantation of amputated fingers, hands, and other parts. A formal residency training program, approved by the AMA, is also offered. Special rehabilitation programs are available for those with congenital facial defects and for hand, eye, and cancer surgery patients. Special rehabilitation is emphasized, and the services of mental health professionals and vocational consultants are offered to assist with vocational problems.

*Information Services:* The Society routinely refers those interested in direct services to local plastic surgeons and clinics. Assistance is provided, if needed, in locating help to pay for the rehabilitation. Individual case reviews and recommendations are sometimes made by teams of specialists from the Institute. If the case is of such a serious nature that only the Institute could help, families are advised of the cost. Fact sheets describing the services of the Institute are available, as well as brochures and pamphlets describing the range of possibilities of such surgery, and giving selected patient histories from the Institute's files. A bibliography of publications by Institute physicians is also available. The Society publishes an annual newsletter, SFD News.

**Spina Bifida Association of America (SBAA)**  
**343 South Dearborn Street**  
**Room 310**  
**Chicago, IL 60604**  
**(312) 663-1562**  
**(800) 621-3141**

*Handicapping Conditions Served:* Spina bifida, with related hydrocephalus.

*Users Served:* Parents, teachers.

*The Organization:* Organized in 1974, the SBAA began and continues a primary emphasis on local parent and patient support groups. Activities also include public education, research, advocacy, and sponsorship of an annual conference for professionals and lay persons on medical, social, educational, and legal issues relating to this disability. A Medical Advisory Board identifies national medical needs and evaluates current medical advances, reporting on these to the membership. The Professional Advisory Board for Education studies current educational programs for children with spina bifida. SBAA continues to work closely with the National Easter Seal Society and the March of Dimes Birth Defects Foundation, and the American Academy of Pediatrics.

*Information Services:* Publications and public education materials are available through 100 local chapters in the U.S. and Canada; chapters also sponsor parent, teenage, and young adult support groups. Publications include The Child with Spina Bifida; By, For and With Young Adults with Spina Bifida; When Something is Wrong With Your Baby; Straight Talk; The Teacher and the Child With Spina Bifida; Giant Steps for Steven; Beyond the Family and the Institution; a bimonthly newsletter, Spina Bifida Insights; and manuals for parents and teachers. Material on organizing SBAA chapters, copy for radio spots, publicity and media presentations, and a directory of chapters can be requested. There is a nominal charge; price lists will be mailed. SBAA will make referrals to local chapters and/or Treatment Centers as necessary.

**Spinal Cord Society (SCS)**  
**2410 Lakeview Drive**  
**Fergus Falls, MN 56537**  
**(218) 738-5252**

*Handicapping Conditions Served:* Spinal cord injury.

*Users Served:* Disabled persons and their families, physicians interested in spinal cord treatment, neuroscientists.

*The Organization:* The Spinal Cord Society (SCS) is an international organization of persons with spinal cord injuries, their families and friends, and dedicated scientists and physicians who are all working toward the ultimate goal of cure through improved treatment methods and research. The SCS raises funds to support a targeted research program aimed at nerve regeneration in the central nervous system. The Society also performs public awareness and community outreach functions. The SCS has over 140 affiliated chapters in the U.S. and Canada.



monitored for improving treatment and guiding research. The case histories are also for screening patients for referral to other physicians or to the SCS Spinal Center, based at the University of Minnesota Hospitals and Clinics.

*Information Services:* Brochures are available describing the activities of the Spinal Society. A newsletter, published monthly, contains up-to-date information on the treatments and research. A subscription is included in the annual membership fee. SCS has a 28-minute film, "The New Epidemic," available to chapters, service clubs and interested groups. A data and referral service is available to SCS members.

**Tourette Syndrome Association (TSA)**  
41-02 Bell Boulevard  
Bayside, NY 11361  
(718) 224-2999

*Handicapping Conditions Served:* Gilles de la Tourette syndrome (TS).

*Users Served:* Disabled persons, parents, teachers, physicians, other health care and educational professionals.

*The Organization:* Established in 1972 by patients and their families, the Association provides information and moral support to others affected by this condition through its more than 100 chapters in the U.S., Canada, and Europe. Tourette Syndrome is a neurological movement disorder, characterized by rapidly repetitive multiple movements called "tics" and involuntary vocalizations. Neuropsychiatric symptoms that characterize this disorder appear in childhood and may be misdiagnosed for an average of 10 years, causing severe psychological damage in the patient and family. For this reason, Association activities emphasize early identification and treatment. Education of professionals and the general public is conducted through publications and the media to alert physicians and families to the signs and symptoms of the syndrome. Since the cause and cure are not known, the Association supports medical research by advocacy, fund raising, and solicitation of autopsy brain tissue for the TSA Brain Bank.

*Information Services:* As the only clearinghouse of information on TS, the Association maintains a current referral file of physicians throughout the country who are working with patients. Exhibits are held at medical conventions each year to acquaint physicians with current research and treatment. The TSA Newsletter reports on new progress throughout the world as well as on activities of local chapters. Lists of insurance companies, TS chapters, bibliographies and article reprints for professionals and parents, membership information, and public education films, "The Sudden Intruder," and "Stop! You Can't" are available on request. Recent publications focus on making Tourette Syndrome understandable to the school nurse, the school psychologist, and service providers. A pamphlet is available in Spanish. Publications are free or available for a nominal charge.

**United Cerebral Palsy Associations (UCPA)**  
66 East 34th Street  
New York, NY 10016

*The Organization:* The United Cerebral Palsy Associations' (UCPA) programs and services are directed toward a two-fold goal--the prevention of cerebral palsy, and meeting the needs of those who are affected by the condition and others who have similar service needs. To fulfill this goal, UCPA: (1) provides funds for research and the training of scientific personnel who work in the fields of prevention and treatment of cerebral palsy; (2) acts as an advocate for the civil rights of disabled persons in the areas of education, employment, independent living, and access to public buildings and public transportation; (3) provides public education programs in schools, hospitals, and community facilities which emphasize prevention of neuromotor problems; and (4) through its 230 state and local affiliates, provides direct services including: medical diagnosis, evaluation and treatment, special education, career development, social and recreational programs, parent counseling, adapted housing for disabled persons, advocacy, and community education.

*Information Services:* Through a variety of publications as well as telephone and letter responses to inquiries, UCPA provides extensive information about the nature of cerebral palsy, the means of preventing the condition, the services available to and required by persons with cerebral palsy and their families, and the civil rights of persons with disabilities. Lay publications include: What Everyone Should Know About Cerebral Palsy, a cartoon booklet describing the causes of the condition, management techniques, available services, and the outlook for prevention; references are made to appropriate publication lists and materials.

In the professional area, UCPA publications include bibliographies on housing, family life skills, sensorimotor performance, and speech; a handbook on transportation; booklets on marketing employment concepts; guidelines for information, referral and follow-along; a respite care manual; nutritional care of the young child with cerebral palsy; six monographs on infant development programs; organizing in-service training workshop guidelines; monographs on teenage programs; and information on advocacy efforts. UCPA publishes a bimonthly general interest newsletter and issues a newsletter dealing with governmental matters of concern to disabled persons. This includes a series of analysis papers on governmental activities affecting persons with disabilities. For professionals and volunteers, the Association's publications include materials on child development; testing, management, and treatment of cerebral palsy; service needs; Federal assistance programs; and fund raising. The Association holds frequent workshops for professionals which focus on upgrading the quality of patient services. Progress in the effort to prevent cerebral palsy is reported periodically in the Research Report and Medical Director's Report. Most information is provided free to any inquirer.

**United Ostomy Association (UOA)**  
2001 W. Beverly Boulevard  
Los Angeles, CA 90057  
(213) 413-5510

*Handicapping Conditions Served:* Ileostomy, colostomy, and urinary ostomy patients.

*Users Served:* Persons with ostomies and their families, health care professionals.

*The Organization:* Formed by an alliance of 28 local chapters in 1962, the Association now has more than 650 chapters in the U.S. and Canada. Volunteers are trained to visit new

and health professionals in the management and care necessary following surgery.

**Information Services:** UOA publishes educational materials explaining the surgery, postoperative care, and living with an ostomy for patients, doctors and nurses. Public information programs are conducted in an effort to eliminate job and insurance discrimination.

Publications include booklets on surgery, management and care for patients. Fact sheets and catalogs describing insurance, equipment, and suppliers, and a quarterly magazine are available. Special problems children may have in accepting their condition, or that adults may have with personal and sexual relationships or childbearing, are dealt with in other publications, all available at nominal cost from the Association.

**United Parkinson Foundation (UPF)**  
360 West Superior Street  
Chicago, IL 60610  
(312) 664-2344

**Handicapping Conditions Served:** Parkinson's disease.

**Users Served:** Disabled persons and their families, health care professionals.

**The Organization:** The United Parkinson Foundation (UPF) is a membership organization for Parkinson's disease patients and their families. UPF assembles information about the disease and disseminates it to members and nonmembers alike. UPF also gives financial assistance to scientists who are studying the disease.

**Information Services:** Booklets on exercise, research and therapies are available at no cost to Parkinson's disease patients and their families, and the information in the booklets is supplemented and updated by UPF's quarterly newsletter. The organization maintains a national list of diagnostic, treatment and rehabilitation centers for the patient, and it can provide the names of retail outlets for obtaining prosthetic devices and special equipment. At the request of the patient, UPF will contact the patient's employer to explain Parkinson's disease and the work limitations, if any. UPF sponsors scientific symposia on Parkinson's disease for lay audiences. Professionals are permitted on-site use of UPF's collection of reprints of scientific papers.

**United Scleroderma Foundation (USF)**  
P.O. Box 350  
Watsonville, CA 95077-0350  
(408) 728-2202

**Handicapping Conditions Served:** Scleroderma.

**Users Served:** Disabled persons and their families, physicians, rheumatologists and dermatologists, other health care professionals.

**The Organization:** The United Scleroderma Foundation (USF) a nonprofit organization

are 28 USF chapters nationwide.

Scleroderma literally means hard skin. Localized scleroderma involves the skin and subcutaneous tissues; systemic scleroderma, which is more serious, can affect the entire body system.

*Information Services:* The Foundation disseminates pamphlets on scleroderma and its various manifestations, the Scleroderma Handbook for patients, and the Scleroderma Digest. Members receive a quarterly newsletter which reports on medical treatment, research, chapter news, workshop information and helpful hints. Many chapters also publish quarterly or monthly newsletters. Accredited workshops are offered through various chapters nationwide. Membership (dues charged) entitles the donor to a full literature packet and four newsletters; otherwise there is a nominal charge for publications. Two brochures are available in Spanish. USF will refer patients and their families to physicians in their areas and to a local chapter if available.

**United Together (UT)**  
**348 Haworth Hall**  
**Lawrence, KS 66045**  
**(913) 864-4950**

*Handicapping Conditions Served:* All disabilities, particularly developmental disabilities.

*Users Served:* Disabled persons, service providers.

*The Organization:* United Together was formed in March 1980 as the result of a meeting of disabled advocates, many of them developmentally disabled, who felt that there was no national organization representing their needs. The purpose of the organization is self-advocacy and the organizational goals were developed from the members' shared belief that all persons should be able to live as independently as possible. The objectives of United Together include: working to assist in legislative change, increasing the availability and variety of community living situations, encouraging more and equitable employment of disabled persons, and improving community awareness of disabled people. This nonprofit organization is made up completely of volunteers, both disabled and nondisabled. Currently, there are ten regional offices to serve the membership of United Together. There is a membership fee for individuals and for groups.

*Information Services:* The organization publishes a newsletter, the UT Quarterly, devoted to promoting concepts of self-advocacy and informing members about the self-advocacy movement across the country. It is available on cassette tape. UT also publishes a brochure describing the goals and activities of the group and curriculum materials on organizing self-advocacy groups. A movie describing the formation of United Together and its purpose of self-advocacy is also available. Organization members provide technical assistance in starting self-advocacy groups and in advocating for specific disability issues. There is a nominal fee for materials, to cover copying or printing costs.

*Handicapping Conditions Served:* All handicaps.

*Users Served:* Disabled persons, parents, teachers, and volunteers.

*The Organization:* Established in 1974, Very Special Arts (formerly the National Committee for the Handicapped) is an educational affiliate of the Kennedy Center for Performing Arts. It disseminates information about curriculum and instruction in the arts for handicapped people and publicizes the need for the benefit of expanded opportunities for handicapped people. VSA sponsors "Very Special Arts Festivals" in 20 sites across the country which offer in-service training to teachers and administrators, workshops and performances by visiting artists, and opportunities for handicapped children to demonstrate or perform in the arts. VSA has conducted research in the areas of model arts programs for the handicapped and in personnel preparation through grants provided by the Department of Education's Special Education Programs office.

*Information Services:* The Committee has compiled lists of national, state, and local organizations with art programs for the handicapped, model sites and other programs which VSA recognizes for excellence, and sources of financial assistance for establishing programs and conducting research projects. Materials about VSA research and demonstration projects and other publications are available for a nominal charge and include reviews of special projects, curriculum ideas for parents and teachers, resource guides and bibliographies. Brochures emphasizing the importance of art, music, dance, and drama for handicapped persons are also available. The VSA Newsletter, published quarterly, contains information about arts programs for individuals with disabilities around the country.

**Vision Foundation, Inc.**  
818 Mt. Auburn Street  
Watertown, MA 02172

(617) 926-4232

(800) 852-3029 (Toll-Free In Massachusetts)

*Handicapping Conditions Served:* Blindness, visual impairment.

*Users Served:* Disabled persons, optometrists, ophthalmologists, social workers.

*The Organization:* Vision Foundation, Inc. is a self-help organization whose primary goal is to assist persons with sight loss in adjusting to their disability and receiving services. In addition to the information and referral program described below, support services are available to persons in Massachusetts and neighboring states, through one local chapter and self-help groups.

*Information Services:* The Foundation operates an information, referral and follow-up center, which handles inquiries on the availability of large print materials and aids and appliances, social security and other benefits and services, travel, housing, employment, recreation, and other areas. The Foundation also distributes materials in large print, braille, and recorded formats, such as catalogs, self-help tapes, and brochures. Vision Views, the Foundation's quarterly newsletter, is a membership benefit available in large print and on

and on voice-indexed cassette. A vision resource list, an annual listing of more than 150 brochures, pamphlets and catalogs, is available free of charge; there is a handling fee for items ordered. While the Foundation primarily serves disabled consumers, professionals working with visually impaired persons will find these publications of interest.

**Wilson's Disease Association**  
**P.O. Box 75324**  
**Washington, DC 20013**  
**(703) 636-3003**

*Handicapping Conditions Served:* Wilson's disease and Menkes' syndrome.

*Users Served:* Disabled persons, parents, physicians and other health care professionals, genetic counselors, and social workers.

*The Organization:* The Wilson's Disease Association is a nonprofit self-help and advocacy group whose main purpose is to give aid and support to the families and victims of Wilson's disease and related diseases. Wilson's disease is a rare genetic disorder characterized by excess storage of copper in the body tissues, particularly in the liver, kidneys, brain and corneas of the eyes. The Association fosters research, disseminates information, disburses funds for research and provides direct financial aid to patients.

*Information Services:* The Association's biannual newsletter contains information on current research, pertinent legislation, and advocacy activities. Pamphlets about the symptoms, diagnosis and treatment of Wilson's disease are available free of charge, up to 50 copies. The Association can refer patients to physicians specializing in Wilson's and related diseases and to researchers. The Association also maintains a data base of articles from medical journals and books that deal with various aspects of the disease.